A Socio-History and Genealogy of Dementia Thought and Conceptualisation in Western Society

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Author Declaration

This thesis is the result of my own work.

It has not previously been submitted, neither wholly or in part, for any other academic award or qualification.

Signed

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(Viva Voce 2018, submitted with corrections 2019)

Abstract

Background: Debates concerning the conceptualisation of dementia in Western society, including its framing as a specific type of disorder (such as neuro-psychiatric, part of the natural aging process, cognitive, and so on) are important in understanding how it has come to be problematized. The manner by which this has been framed has implications not only for the perceived disciplinary ownership of dementia, but also for the lived experience of people diagnosed with dementia, their families, and the care professionals and nurse educators supporting them or their carers. The work of Michel Foucault is useful in setting this debate within a critical socio-historical context. **Aims:** The problematization and conceptualisation of dementia in Western society, including its socio-history, is re-examined, drawing on an approach influenced by Foucault's history of problematization. Here, through exploring alternative conceptualisations, using a Foucauldian critical history, this study reviews society's understanding of what it is to be a person with dementia. The aim of this study then is to challenge dominant neuro-psychiatric conceptualisations of dementia in Western society and to examine and explore how alternative conceptualisations have existed through our history. This requires taking a critical review of the historical evidence of the different ways of seeing, speaking about, or understanding dementia and its subsequent problematization. **Methods:** An in-depth analysis of 500 documents, spanning 4,000 years, covering early Egyptian, Greek and Roman periods, through to the twenty-first century, are examined. These were sourced through academic databases and archival sources as well as snowball sampling from reference lists and bibliographies. Based on carefully considered inclusion and exclusion criteria, including personal reflexivity and consideration for researcher bias, relevant documents were compiled into an *Archive* representing a socio-history of dementia thought. Framework analysis was then used to examine the manner in which dementia is conceptualised and problematized in different texts or fields of discourse taken from the *Archive*, and emerging analytical themes were then interpreted using Foucauldian analysis. **Results:** Six differing conceptualisations or problematizations of dementia were found (as a

natural consequence of ageing, a mental or neuro-psychiatric disorder, a bio-medical disorder, a neuro-cognitive disorder, a disability; and, a terminal illness). **Conclusion:** What it is to be a person with dementia is located within a particular conceptual framework, with ideas or considered truths about the condition reliant upon historically-contingent assumptions. It is here, through understanding the inter-connectedness, dominance, and the subjugation of dementia discourse, we are able to understand a range of possibilities in how we 'make up people' (classifications based on social determinants) with dementia. Through this critically reflective position, taken-for-granted assumptions about dementia are called into question.

Dedication

This study is dedicated to my amazing fiancée Maria Leedham and our happy future together, as well as to my late father and mother in memory of their unconditional support and love.

A special recognition is also made to my sister, Mary, my brothers and sister-in-law, Sam, Jess, Brian and Martha, my godmother Aunty Jenny, the memory of my late close friend Dot Hemel, and also my growing family with Marg, Holly, and Joe.

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Contents

Glossary of abbreviations

Aβ	Beta-amyloid protein
AD	Anno Domini
AD	Alzheimer's Disease
ADL	Activities of Daily Living
ADL-IS	Alzheimer's Disease Activities of Daily Living International Scale
ADRC	Alzheimer Disease Research Centre
ADRDA	Alzheimer's Disease and Related Disorders Association
ALD	Adrenoleukodystrophy
ALS	Amyotrophic Lateral Sclerosis
ADCA	Autosomal Dominant Cerebellar Ataxia
ADFACS	The Alzheimer's Disease Functional Assessment and Change Scale
APA	American Psychiatric Association
APOE	Apolipoprotein
APP	Amyloid Precursor Protein
BC	Before Christ
BCE	Before Common Era
B-ADL	Bayer Activities of Daily Living Scale
BANS-S	Bedford Alzheimer Nursing Scale-Severity Subscale
BND	British Nursing Database
BNI	British Nursing Index
BNT	Benton Naming Test
BRC	Brain Reserve Capacity
BRSD	Behaviour Rating Scale for Dementia
bvFTD	Behavioural variant of Frontotemporal Dementia
CAD-EOLD	Comfort Assessment in Dying – End Of Life in Dementia
CADSIL	Cerebral Autosomal Dominant Arteriopathy with Subcortical Ischaemic Leukoencephalopathy
CAPE	Clifton Assessment Procedures for the Elderly

CASI	Cognitive Abilities Screening Instrument
CBD	Corticobasal Degeneration
CDR	Washington University Clinical Dementia Rating Scale
CE	Common Era
CJD	Creutzfeldt-Jakob Disease
CMRT	Continuous Recognition Memory Test
CSADL	Cleveland Scale for Activities of Daily Living
CT	Computerized Tomography
CTX	Cerebrotendinous Xanthomatosis
DAD	Disability Assessment for Dementia
DH	Department of Health
DLB	Dementia with Lewy Bodies
DRS	Mattis Dementia Rating Scale
DS-DAT	Discomfort Scale for Dementia of the Alzheimer Type
DSM	Diagnostic Statistical Manual
EoLD	End of Life in Dementia
FAS	Verbal Fluency Test
FAST	Functional Assessment Staging
FAQ	Functional Activities Questionnaire
FAVS-D	Family Visit Scale for Dementia
FDA	United States Food and Drug Administration
FTDP-17	Chromosome 17q21 (contains the gene for making tau protein)
FTLD-U	Frontotemporal lobar degeneration-ubiquitin
FTD	Frontotemporal Dementia
fvFTD	Frontal Variant Frontotemporal Dementia
GDS	Global Deterioration Scale
GDS	Geriatric Depression Scale
HAD	Human Immunodeficiency Virus-Related / Associated Dementia
HD	Huntington’s Disease
HDS-R	Revised Hasegawa Dementia Scale

HE	Hashimoto's Encephalopathy
HEDN	Higher Education Dementia Network
HEI	Higher Education Institute
ICD	International Classification of Disorders
iPS	induced Pluripotent Stem
MMSE	Mini-Mental State Examination
MND	Motor Neurone Disease
MPES	Menorah Park Engagement Scale
MRC	Medical Research Council
MRI	Magnetic Resonance Imaging
NIA	National Institute of Ageing
NICE/SCIE	National Institute of Health and Clinical Excellence/Social Care Institute Excellence
NIS-S	Neuropsychological Impairment Scale
NPI	Neuropsychiatric Inventory
NSC	Neural Stem Cells
OLD	Observation List for Early Signs of Dementia
PAINAD	Pain Assessment in Advanced Dementia
PCR	Polymerase Chain Reaction
PML	Progressive Multifocal Leukoencephalopathy
PNFA	Progressive Non-Fluent Aphasia
PSP	Progressive Supranuclear Palsy
QUALID	Quality of Life in Late-Stage Dementia
RADL	Refined ADL Assessment Scale
RTC-DAT	Restiveness to Care-Dementia of the Alzheimer Type
SCT	Stem Cell Transplantation
SD	Semantic Dementia
SM-EoLD	Symptom Management – End of Life in Dementia
SMMSE	Standardized Mini-Mental State Examination

SOAPD	Scale for Observation of Agitation in Persons with Dementia of the Alzheimer type
SPECT	Single-Photon Emission Computed Tomography
SWC-EoLD	Satisfaction with Care – End of Life in Dementia
Tar	Trans-Activating Responsive
THA	Tetrahydroaminoacridin, also known as ‘tacrine’
TSI	Test for Severe Impairment
Tau	Tubulin-Associated Unit
tvFTD	Temporal Variant Frontotemporal Dementia
UK	United Kingdom
VD	Vascular Dementia
WHD	Whipples Disease
WHO	World Health Organisation

Chapter 1: Introduction

1.1 Background and context

The number of people diagnosed with dementia in the United Kingdom (UK) is increasing (Alzheimer's Society, 2005), and is forecast to be 940,000 by 2021 (Knapp, *et al.*, 2007), 1,142,677 by 2025 and 2,092,945 by 2051 (Prince, *et al.,* 2014). A three-fold rise globally within the next 40 years is also expected (Ferri, *et al.*, 2005). Recent figures suggest about 670,000 people in the UK currently have dementia (Mathews, *et al.,* 2013), whilst the Alzheimer's Society (2014b) suggests this is higher, with an estimated figure of 850,000. Whatever the actual number, it is high, and numbers will continue to rise for the foreseeable future (Dening and Sandilyan, 2015). This predicted rise has increased attention to be put on the education of practitioners caring for people with dementia through what has been termed the 'dementia curriculum,' which has been growing in popularity within higher education institutes (HEI's) (Knifton, *et al.,* 2014). Dementia education spans a wide range of professional educational programmes emerging over the years (for example Alushi, *et al.,* 2015; Baille, *et al.,* 2016; Beer, *et al.,* 2009; Board, *et al.,* 2012; Bradley, *et al.,* 2010; Brody and Galvin, 2013; Downs, *et al.,* 2009; Dunphy, *et al.,* 2010; Elvish, *et al.,* 2014; Fruhauf, 2007; George, *et al.,* 2011a; Hasselbach, *et al.,* 2007; Irvine, *et al.,* 2013; Kaf, *et al.,* 2011; Lichtenberg and Hedge, 2009; Moorhouse and Hamilton, 2014; Paquette, *et al.,* 2010; Pulsford, *et al.,* 2007; Smythe, *et al.,* 2014; Surr, *et al.,* 2016; Tullo and Allan, 2011; Tsolaki, *et al.,* 2010; Waugh, *et al.,* 2011; While, *et al.,* 2010). Here, dementia education research shows fluctuating periods of interest before an eventual culmination, noted between 2014-2016, for ideas that focus and settle for the distinct positioning of person-centred care as the dominant discourse and research agenda. Although this has led to a focus on how best to develop person centred training in dementia, it neglects any critical exploration for other ways in which dementia could be considered or problematized. This leaves less

opportunity to research and discover new or subjugated ideas, clearly limiting our understanding of how dementia has come to be conceptualised.

Understanding this research agenda and focus provides an important backdrop for this study, giving an early indication of ideas, gaps, and current conceptualisations. Attempting to critically understand the drivers of the current research agenda becomes noteworthy, particularly as any problematization of dementia (and thus, what governs the research agenda) is maintained within systems of thought and practice that govern what can and cannot be said. The majority of research in dementia education is driven through HEIs and as such, it is important to critically reflect on how this has contributed to the dementia education research agenda and focus. One way of doing this is to briefly reflect on how REF2014 has contributed to research on dementia education.

The Research Excellence Framework (REF) is a system used in HEIs across the UK to assess the quality of research outputs. Beginning with preparation for REF in 2011 in readiness for REF2014, the type of research to be carried out by HEIs would have been affected. All four UK higher education funding bodies allocate research funding to HEIs based on their REF results. Importantly also, they appoint their own REF panel members, a process of expert review. Outputs, including publications, their impact beyond academia and the environment that supports this, are all assessed, and remain a central driver in UK research policy (Watermeyer, 2012). This has created a national assessment of the relationship between research and its impact, with clear financial incentives (Clarke, 2015; Wilkinson, 2019). Consideration of how the REF may affect the number and type of publication outputs seen in recent years, relevant to dementia education, is important. This is because the REF has the potential to influence dementia education research in a number of ways due to its focus on, inter-disciplinary research (Bastow, *et al.,* 2014), supporting research that may otherwise have been overlooked (Wilkinson, 2019), public and service user engagement (Watermeyer, 2012), and research that makes a contribution to society (Wilkinson, 2019). Critically however, it could also restrict research activities in dementia education. This has included pre-REF 2014 second-guessing as to

what activities might be high scoring (Watermeyer and Hedgecoe, 2016) and the practicalities of evidencing or capturing impact (Manville, *et al.,* 2015). Now published, the impact of REF 2014 on dementia research is noteworthy. Three units of assessment (UoA) of relevance to dementia education were examined (UoA 3: Allied Health Professions, Dentistry, Nursing and Pharmacy; UoA 4: Psychology, Psychiatry and Neuroscience; and, UoA 25: Education). They showed no recorded outputs on the subject of dementia education and equally there were no impact studies on dementia education either. REF2014 thus did little to support dementia education research and may even have left the area side-lined in favour of primary intervention research (such as psycho-social, assistive-technology, cognitive or pharmacological studies and their effect on the symptoms of dementia). In particular, some of the research on dementia education, as cited above, would have been published in time for REF2014 (2011-2014) consideration. Yet none of the studies cited featured in the institutions REF submission. Again, this is likely the impact placed on the importance of dementia education research. Whether or not this will change for REF2021 is worthy of consideration, especially considering the importance now being placed in having a highly skilled dementia workforce (World Health Organisation [WHO], 2012).

Here, we find the Government arguing the need to prioritise and improve the training and development of the dementia workforce (*ibid.*). This emerging cultural awareness and societal commitment to dementia education has supported health and social care professionals to see beyond 'the disease' of dementia and its once psychiatric medicalisation. Instead, as noted above, there is a general acceptance for 'person-centred' concepts of dementia (Department of Health (DH), 2009; DH, 2010; National Institute of Health and Clinical Excellence / Social Care Institute for Excellence (NICE/SCIE), 2006; Skills for Care/Skills for Health, 2011). This person-centred approach is now the essential focus embedded within contemporary dementia curricula, with little discussion of or for alternative conceptualisations.

Whether it is through HEI research, guidance reports, or Government initiatives, concerns over dementia knowledge and the education of professionals still remain (All Parliamentary Group on Dementia, 2009; Knifton, *et al.,* 2014; Pulsford, *et al.*, 2007). Although Fox (1989: 58) once wrote that "public awareness of Alzheimer's disease has increased dramatically within the last ten years," now, exactly 30 years on, what this awareness includes, and what this says about what it is to be a kind of person with dementia, (how society chooses to classify people), still requires contextualising.

Despite the support for person-centred approaches, the current conceptualisation of dementia in Western society remains focused on nosological systems of understanding that continue to present it as a mental disorder; defined, diagnosed, assessed, managed and taught, largely through the field of psychiatric medicine and mental health nursing. This largely neuro-psychiatric way of seeing dementia remains the dominant model in Western society (Downs, *et al.,* 2006), despite growing calls to see beyond the disease (Kitwood, 1993a, 1993b), suggestive of dementia care practice over rhetoric. This continued neuro-psychiatric conceptualisation problematizes dementia in a way that maintains the need for diagnosis, further assessment, and ongoing care to be monitored and/or managed through a variety of specific mental health services. Knowledge and power surrounding the conceptualisation of dementia are left entrenched within medicine, particularly psychiatry, with mental health nursing, for example, dominating the majority of dementia services, as well as a growth in professions such as old age psychiatry (Downs, *et al.,* 2006). This mental health disciplinary focus as the nursing field of practice for dementia nursing care, is also reflected through nurse education curricula. Consequently, recruitment for dementia nursing posts expect registration as a mental health nurse as being a desirable, if not an essential, nursing qualification. Psychiatry thus continues to maintain its dominance in the journey of care for the person with dementia, reinforced through the education of professionals, despite the growth of person centred care models that offer alternative views (Kitwood, 1997; Morton, 1999; Bird, 2000; Sabat, 2001; Stokes, 2003; Brooker, 2004; Love and Pinkowitz, 2013; Brooker and Latham, 2015; Mental Health Foundation, 2015). Despite a clearly advocated

person centred rhetoric, the bio-medicalisation of dementia and the consequential dominance of psychiatry become the reality and lived experience for many people diagnosed.

Consequently, dementia education remains dichotomous, with a contrast between disease/neuro-psychiatric medicalisation and with approaches that see beyond the medicalisation of the disease, including person-centred care and a growth in social disability models. Awareness of such contrasting possibilities in how we understand dementia, including how and why we have come to problematize dementia in this way, and the power and disciplinary ownership of dementia, are clearly important for shaping curricula and understanding current conceptualisations. As noted by Whitehouse, *et al.,* (2000):

> "it is ironic that the professional and popular discourses surrounding Alzheimer disease (AD), whose most dreaded feature is the obliteration of memory, proceed with little awareness of its past... caregiving efforts that surround AD require a sense of history in order to situate themselves in the present and orient themselves toward the future" (2000: xi).

The potential for alternate ways of seeing dementia have also been found to include viewing it as a neurological condition or as part of normal ageing (Downs *et al.,* 2006), which questions our understanding about what it is to be a person with dementia and how it becomes problematized in a certain way. This becomes the focus of this study – a wider search for the possible conceptualisations of dementia in Western society and to understand why mental health, or psychiatry, is seen as the dominant discourse, if indeed this is still the case. This will be achieved through a socio-historical analysis of power, knowledge, and truth in conceptualising the condition, or rather, a general socio-history and genealogy of dementia conceptualisation in Western society.

In this introductory chapter, we begin with a brief discussion on what is meant by Western society. This is an important consideration worthy of exploration, as different societies and cultures will have differing socio-cultural histories in their relationship to dementia. The study will then discuss what it means by dementia, followed by a critical reflection on the perceived dominance of psychiatry in

contemporary Western society. The study then begins to introduce the work and influencing ideas of Michel Foucault, key in critiquing and analysing the phenomenon of dementia through a socio-history of its problematization. This provides the study with a useful starting point in which to present its research question, clarify its research aim and objectives, and to provide an overview of the study as a whole.

1.2 Western society

This study focuses on a specific history of dementia bound by social and cultural systems found in Western society. However, the very use of the term 'Western society' becomes in itself problematic. Potentially any definition offered may fail to recognise its complexity. No definition, it could be argued, would be without its critics. This creates a clear challenge, necessitating a need to clearly articulate, or rather de-limit, the terms in which Western society will be used for the purpose of this study, acknowledging any historical, ethnic and geographical limitations.

This study considers Western society as meaning the Western world, including Europe, America and Australasia, importantly making it applicable to countries where there is a history of European emigration. The term 'Western' is specifically chosen in order to trace a specific historical trajectory through systems of thought and institutional/disciplinary practices that connect it to modern Western medical or psychiatric conceptualisations. Considering here European emigration as a starting point to understand Western society is important, because it includes the spread of ethics, values, beliefs, customs, art, politics, philosophy and technology - making historical early associations with ancient Greece and Rome (the Greco-Roman period). This also included the growth of religious and cultural traditions, beliefs, values and customs largely through Judaism and Christianity (commonly known as Judaeo-Christian), supporting a Western culture and system of thought with its own disciplinary practices and evolving social institutions. With European emigration/colonialism, the borders of Western society changed and move back

and forth throughout history to include not only Europe but also the United States of America, Australia, northern Africa and some parts of the Middle East.

It is important therefore, to consider the possibilities that this distinction between Western and thus non-Western societies may create; a principle of ‘otherness’. This suggests these other societies are united by the fact that they are inherently different to the West. This poses an ethical risk in implying that it acts as a standard by which other non-Western societies may be judged (see for example Hall, 1992). There is also a risk in failing to recognise global variation and heterogeneity, noting that Western society is also not homogenous; with clear differences existing between the UK, Europe, Australia and the United States of America, Northern Africa and some parts of the Middle East. This can be due to differences between economic, legal and political structures, professional power and histories of resistance. Added to this, any Western society will also have its own minority communities, including co-existing cultural variations. Here, using the term ‘Western society’ risks marginalising various communities in European countries whose cultural origins are non-Western.

The term ‘Western society’ therefore is used purely advisedly in order to delineate a specific tradition within which to situate this study’s historical analysis. There is no intention for the term to carry any wider significance than this. There is however an understanding and recognition of its limitations and problems when used in this way.

In summary, the understanding of Western society, as will be used in this study, is not one of an epistemological template for thinking about dementia purely on a basis of distinction between the West and others. It is neither a deliberate attempt to ignore established minority communities within Western society or ignore their economic, legal and political differences. Rather, the explicit reference to Western society is only one example of a ‘general’ (and not a ‘total’) definition. It includes tracing it to ancient Greece and Rome; reflects prevailing Judaism and Christian values, beliefs, practices and influences; includes countries with a history of European emigration; is based on principles of rationalism, empiricism, political pluralism and individualism; and, recognises global differences as well

as inter-society cultural variations based on Judaeo-Christian beliefs. The understanding of Western society, as used in this study, is based on historical connections between ancient communities or civilisations with systems of knowledge and thought that reflect these principles, linked also by patterns of movement that are linked to current practices. Our definition of Western society is thus, one of a 'general', rather than a 'total' understanding.

1.3 Dementia

Dementia is an umbrella term used to describe a set of symptoms caused by a variety of diseases (Knifton, 2009). These diseases are usually chronic, progressive, and life-limiting, leading to a continued decline in mental and cognitive functioning (Dening and Sandilyan, 2015). They typically result from a range of structural and chemical changes in the brain. The resulting destruction and death of brain cells are associated with our common understandings of dementia (Brotchie, 2003). The term dementia is used to describe an array of conditions, diseases or disorders fitting this description, made up from a range of pathological entities (Ferri, *et al.*, 2005), that cause progressive brain deterioration. However, no definitive studies give the precise number of diseases that may lead to dementia (also known as dementia sub-types). The Alzheimer's Society (2007) suggest over 100 dementia sub-types, whilst Stephan and Brayne (2010) and Ashton (2016) suggest this figure may be closer to over 200. The International Classification of Mental and Behavioural Disorders (ICD-10) (WHO, 1992) lists examples of dementia subtypes to include Alzheimer's disease, vascular dementias (including both multi-infarct, subcortical and mixed cortical), Pick's disease, Creutzfeldt-Jakob disease, Huntington's disease, dementia in Parkinson's disease, Human immunodeficiency virus-related dementia (HIV), and unspecified dementia, whilst the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (APA, 2013) also includes Frontotemporal neurocognitive disorder, neurocognitive disorders with Lewy bodies, traumatic brain injury, substance/medication-induced neurocognitive disorder, or disorders due to prion disease. Dening and Sandilyan (2015) argue that common forms include

Alzheimer's disease, Vascular dementia, Dementia with Lewy bodies, and mixed dementia; and less common forms as Huntington's disease, corticobasal degeneration, Creutzfeldt-Jacob disease, multiple sclerosis, normal pressure hydrocephalus, and HIV-related dementia. This range of dementia sub-types illustrates the broad and varied conditions that make up this disease, as also was noted by Alzheimer who was quoted as saying:

> "We must reach a stage in which the vast well-known disease groups must be subdivided into many smaller groups, each with its own clinical and anatomical characteristics." (Maurer, *et al.,* 2000:20).

Regardless of dementia type, the symptoms to first appear usually include a succession of orientation problems. To talk about a person with dementia generally also indicates someone who presents with symptoms of short-term memory loss, as well as problems with performing activities of daily living and other associated cortical functions (NICE/SCIE, 2006). As dementia develops, behavioural and psychological symptoms may also occur (Burns, *et al.,* 2002). Dementia is the result of organic brain damage and pathological change to various anatomical sites in the brain, depending on the dementia sub-type. Alzheimer's disease for example, the most common sub-type of dementia (Dening and Sandilyan, 2015), begins with structural changes to the hippocampus, whilst frontotemporal dementia initially affects the frontal lobe of the brain. Another important feature of dementia is that it largely remains a disorder of later life (65 years or over), with incidence and prevalence rising with advancing age (DH, 2009). However, dementia can also affect people of working age, referred to as 'early onset' or 'pre-senile' dementia, with even some rarer juvenile forms known to affect children (Fernandez-Bouzas, et al., 1992), such as Niemann-Pick C Disease.

1.4 The presumed dominance of psychiatry in dementia care and its effect on nurse education

Definitions of dementia highlight its construction as a biomedical disease or as a neuro-psychiatric condition (Downs, *et al.,* 2006). This is evidenced in contemporary classifications such as the Diagnostic and Statistical Manual of Mental disorders (DSM-5) (American Psychiatric Association (APA), 2013) and the International Classification of Disorders (ICD-10) (WHO, 1992), but also through professional guidance papers and reports that point towards these same assumptions (NICE/SCIE, 2006). For health and social care professionals, current guidance on the diagnosis, treatment and management of a range of illnesses, diseases and disorders within the UK is produced by the National Institute for Health and Clinical Evidence (NICE). Established in 1999, as a special Health Authority for England and Wales, NICE has a clear remit to provide a single source of authoritative and reliable guidance, based on what it calls 'the most-to-date and robust evidence base' (NICE/SCIE, 2006:44). Of particular relevance to dementia care is the NICE/SCIE guidance on dementia (NICE/SCIE, 2006). Of interest is the recognition of what may be viewed as the 'medical model of dementia', and reference to the International Classification of Diseases (ICD) – 10 (WHO, 1992) definition which NICE closely refers to;

> "a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capability, language and judgement. Consciousness is not impaired. Impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. The syndrome occurs in Alzheimer's disease, in cerebrovascular diseases, and in other conditions primarily or secondarily affecting the brain" (WHO, 1992:45).

The significance of referring to the medical model and its focus on traditional psychiatric symptoms of 'deterioration in emotional control, social behaviour or motivation' are important when understanding the role played by psychiatry. As Innes (2009) argues, such biomedical constructions, including definitions provided by the World Health Organisation (2001) (cited by Innes, 2009:4) and even the Alzheimer's Society (2006) actually tend to hide the 'knowledge generation' that underpins such statements. What they thus create, in effect, is an 'acceptance' of the medical model.

Accordingly this has a knock-on effect for nurse education. Studying dementia currently involves investigation into the outcomes of developments that have contributed towards its medicalisation – the signs, symptoms, and pathology that feature within recognised classification systems and the application of this to practice. There is little discussion directed at understanding the power, knowledge and truth that underpins such contemporary definitions within dementia knowledge, which as Innes (2009:4) has argued, leaves it being "partial, flawed and incomplete". This has led to an uncritical acceptance and support for bio-medical definitions that are found in contemporary systems of classifications, and consequently nurse education continues to reinforce psychiatric control and dominance. Mental health nurses thus, take on a large role in dementia care, which in return reinforces psychiatric conceptualisations.

1.5 Significance and rationale for the study: conceptualising dementia

Disputes that dementia is not purely a natural consequence of ageing remain (Gubrium, 1986), with arguments that it has a distinct disease pathology, although critiques to any overt medicalisation of dementia do also exist (Bond, 1992; Estes and Binney, 1989; Lyman, 1989). Supported by detailed histories reviewing the dominance of bio-medicine, a number of writers begun to advocate that dementia may in fact be, in some part, a socially constructed disease (Ballenger, 2006a, 2017; Harding and Palfrey, 1997; Innes, 2009; Whitehouse, *et al.,* 2000). Some of these narratives are however incomplete, for they fail to examine the contingencies that support the production, strengthening and maintenance of any advocating dominant dementia discourse. The move from conceptualising dementia as a natural consequence of ageing to its bio-medicalisation is evidence in how this condition can be re-conceptualised. Downs *et al.,* (2006) discuss other conceptualisations of dementia and highlight the 'person-centred perspective' and 'neurological condition' as additional examples, although how these differing conceptualisations came to emerge, their genealogy, is still absent. Crucially,

their paper highlights a potential for identifying different discourses of dementia. This is where ideas for our study emerge. It is hoped that through a careful examination of a range of historical and contemporary documents, of their discourses and emerging themes, that this study would discover a series of alternative conceptualisations. Downs, *et al.,* (*ibid.)* suggest that the way society explains dementia becomes based on a particular intellectual paradigm that has shaped the way the condition is seen. This idea is key to this study. Noted by Dyson and Brown (2006):

> "What is seen to be there is actually the product of particular sets of power relationships. The implication is that in other sets of power relationships a very different reality could be produced" (2006:54).

As also argued by Rosenberg, "in some ways disease does not exist until we have agreed that it does, by perceiving, naming and responding to it" (1992a: xiii). A more integrative approach to understanding dementia, which as well as bio-medicine, also includes social science and the medical humanities, is needed (Portaclone, *et al.,* 2014). Consequently, a critical socio-history of dementia is warranted, achieved through adopting a post-structuralist approach to analyse explanatory constructs of dementia and its problematization.

1.5.1 Power, knowledge and truth

As argued by Kitwood (1995), the present construction of dementia is not a direct consequence of biomedical science, but rather derived from social interests and economic opportunity. Social forces keep the contemporary construction of dementia 'in its place' and thus require analysis. This includes an understanding of not only how people with dementia are classified, but also both the effects that this classification may have on them, and how this may then come to re-affect the original classification. This is sometimes known as the 'making up of people' with dementia. This term, *'the making up of people,'* is associated with the work of Hacking (2007) who originally coined the phrase in the 1980's (Hacking, 1986). This, as well as the 'looping effect' (Hacking, 1996), referring to the classification

of people, how these classifications then affect these people, and finally how the classified people can then re-affect any original classification, reflects this idea of the social construction of dementia. Hacking's own philosophical thinking was influenced by Foucault (Hacking, 2009:82), and supports a historical approach which Hacking attributes to Foucault, known as 'dynamic nominalism' (Hacking, 2007:295). This approach follows a similar tradition of post-structuralism and is important in understanding how the principles of Foucauldian analysis may be applied to this study, particularly in recognising what kind of person it is to be a person with dementia. This is because Foucault in particular saw power as comprising those regulated means that effect the actions of others in society, including the structural relationships between the person and society. These remain inextricably linked to both the formation and operation of the social apparatus. The amenability of the person to this social apparatus leads this study to question who has the authority to speak of dementia; the desired intervention or dementia care management goals; changing forms of the social apparatus that people with dementia and their family's become part of; and finally, what is to be done with or to the person with dementia.

1.5.2 The work of Michel Foucault and Foucauldian analysis

One way of investigating power, knowledge and truth in conceptualising dementia is through a detailed post-structuralist approach, or Foucauldian examination of a general history of dementia thought and its problematization. Foucault's ideas are useful here because of his attention to reconceptualising how power, knowledge and truth are constructed. Importantly Foucault links power directly to knowledge (Foucault, 1980; 1978 [1976]), important if reviewing the bio-medicalisation of dementia and the perceived dominance of psychiatry in practice or/and person-centred care rhetoric. In this way, the construction of what we identify as dementia is a complex production of a particular way of thinking – what Downs *et al.,* (2006:209) call the "explanatory constructs to locate dementia within particular intellectual paradigms". As dementia emerges as a specific object of thought, then so will particular ways of thinking and acting about

dementia. This creates the possibilities of thought that permit a series of power relationships that continue to maintain these ideas, or truths. Alternative ways of thinking about dementia, or its forms of problematization, would, according to Foucault, be linked to different operations of power and governance. Foucault's work and methods are crucial to this analysis as they provide us with this unique way of understanding power, knowledge and truth (Foucault, 1983; 1989a; 1997). In particular for Foucault, it was only through a detailed and critical examination of the history of the problem that we could understand and make sense of its present. This is the approach taken in this study; a socio-history on the problematization of dementia. In understanding the changing problematization of dementia this study hopes to find new ways of thinking about dementia, and the effect of society in its framing as a disorder.

This approach aligns itself with the traditions of post-structuralism, complete with an already established series of methodological practices used throughout health and social care research (see for example, Nettleton, 1992; Heaton, 1999; Powell and Biggs, 2003; Yates, 2015). This approach questions total histories and teleological constructions, and instead attempts to expose the potential inadequacies of dominant forms of thinking (such as problematizing dementia as a neuro-psychiatric disorder, or as a consequence of normal ageing, or within the rhetoric of person care practices).

1.5.3 Framework and documentary analysis, archaeology and genealogy

Implicit to Foucault's thinking, is that at any given time, substantial constraints on how people think are also operating. Essentially this includes a range of implicit rules that act to restrict the range of thought within, for example, specific time periods – rules that then act to both constrain and to permit thought. It is these rules (or 'contingencies') which need uncovering. Although this remains a historical approach, it relies also on the uncovering of the apparent surface effects and specifics of language – what Foucault referred to as the *'sedimentary strata'* (Foucault, 1972 [1969]:3). When applied to this study, it is not just what is being

said about dementia through history (as may be found in many total histories), but instead it is about the underlying structures that form the context for thinking about dementia in a certain way. This includes, for example, the basis for dementia's scientific discoveries and the creation of systems for its changing classification. The result is a study of the general history of dementia.

In this general history of dementia, the analysis concentrates on "describing differences, transformations, continuities, mutations and so forth" (Foucault, 1972 [1969]:10). As noted by Dean (1994), this type of historical analysis gives attention to a type of detail and complexity that moves far beyond the mere caricatures of historical periodization. Discovering discontinuities and ruptures in thought and practice instead become research objectives, examining the means by which discourses gain foundation, transform, and then appear, disappear and re-appear again.

One methodological approach to do this is through a carefully considered approach of document selection and analysis (Foucault, 1977 [1975]), such as Framework Analysis (Ritchie and Spencer, 1994). Starting with a clearly defined document inclusion/exclusion criteria, a systematic search was undertaken to gather relevant documents, forming what was later termed the Dementia *Archive*. Careful familiarisation of these documents followed, including data immersion with discourse abstraction and analysis. Retrieved discourse was then sifted and sorted within the context of a thematic framework that also ordered and grouped discourse into subject areas, producing genealogical concepts and a series of problematizations. This method of analysis was further developed to ensure that the discourse contained within documents remained associated with the mechanisms of power that had led to their creation (Foucault, 1991). This is because knowledge and power are logically compatible (Foucault, 1977 [1975]). This remained a key focus in developing our 'genealogy', a method also adopted by Foucault in his research on the history of the prison (Foucault, 1977 [1975]) and the history of sexuality (Foucault, 1978 [1976]).

Genealogy guides the researcher to look beyond just the language of the discourse used to describe the found conceptualisations of dementia, but to also

examine the mechanisms of power that have led to any changes in conceptualisations too. The genealogical approach thus adds to descriptions of systems of thought, derived from the archaeological method of finding discourse, to further explain conceptual changes, by paying attention to processual aspects of discourse (Foucault, 1981); studying the processes rather than discrete historical events in the discourse.

There are, it should be noted, a number of ways in which investigating how dementia is conceptualised can be undertaken, including phenomenology and interview approaches. Although these methods have their merits and could provide a possible answer, they may only reveal current or dominant ideas that lack any socio-historical underpinning or understanding of why or how this thinking takes place. Although answers as to how dementia has come to be problematized could be revealed, how it came to be problematized in this way will likely be missed.

Based on our approach, current conceptualisations of dementia, such as its medicalisation as a neuro-psychiatric condition, the dominant explanatory model in Western society (Downs, *et al.,* 2006), are not taken for granted. Instead, this study contends that what we choose to call dementia is considered the product of historically situated knowledge with a potential to be exposed through our methodological archaeology, genealogy and socio-history. Thus this methodological approach does not see dementia as a condition that can be unproblematically researched, but rather as an object or 'kind' constituted by a range of discourses, shifts and ruptures that have led to its present neuro-psychiatric problematization. This study thus presents dementia as a history of conceptual thought (socio-history and genealogy), based on a history of its problematization, providing a unique contribution to the knowledge and understanding of dementia.

1.6 The research question

This study sets out to examine a socio-history of dementia and its problematization, and asks;

'How is dementia conceptualised in Western society?'

1.6.1 Study aim and objectives

Aim:

To challenge dominant neuro-psychiatric conceptualisations of dementia in Western society and to explore alternative ways of seeing, speaking about, or understanding, dementia and its subsequent problematization.

Objectives:

(a) Analyse ways we have come to speak about dementia identifying not only terms used to denote this condition, but also any potential differences in how these terms come to be used.

(b) Construct a comprehensive database of documents that describe dementia in a variety of ways. Develop appropriate inclusion and exclusion criteria, apply to this database for document selection, and produce a final list of documents, referred to in this study as the *Archive,* ready for analysis.

(d) Carry out an in-depth analysis of the *Archive*, using framework analysis as a structure, and discourse analysis as a process used to interpret and chart discourse surrounding the problematization of dementia throughout its socio-history.

(e) Reflect on the implications of problematizing dementia throughout its socio-history and its potential impact.

1.7 Structure of the study

This chapter has introduced the general background and rationale underpinning this study, its research question, central aim and objectives. **Chapter 2** discusses in more detail why a socio-historical analysis is best suited to reach the aim of this study. **Chapter 3**, provides a review of the literature on the history of dementia, including the limitations of using a total history approach that focuses solely on periodization and scientific discoveries. Instead, this chapter argues a new approach, a general history of conceptualisation and problematization as set out in this study, is warranted, complementing ideas proposed in the pre-ceding chapter. **Chapter 4** outlines in detail this study's research methodology in developing and analysing this socio-history, using documentary research, framework analysis, as well as the principles of Foucauldian analysis and post-structuralism, as ways of analysing and interpreting discourse. **Chapter 5** presents two sets of findings. First, an 'archaeology' of dementia is proposed, based on the creation of the *Archive*. Secondly, a genealogical enquiry, presented as key themes of discourse uncovered through a socio-historical enquiry is shown. This is based on a detailed analysis of truths, power/knowledge and technologies of self in the 'making up' of people with dementia that give rise to a series of problematizations; essentially an analysis of the mechanisms of power at work. In **Chapter 6** the phenomena of dementia as one of problematization is further explored, located within the context of power, knowledge and truth. In the final chapter, **Chapter 7**, our research question, *'How is dementia conceptualised in Western society?* becomes answered and conclusions are drawn on the potential implications, including study recommendations.

Chapter 2: Historical research, historical sociology and post-structuralism

2.1 Introduction

The history of dementia is not a new topic for analysis and so this study needs to justify what unique contributions it may be able to make. In particular, questions need to be addressed as to what makes this study different from other previously published literature reviews on this topic. This chapter then is intended to defend the epistemological position that a new approach, a general history, based on the post-structuralism and Foucauldian principles as taken in this study, is needed. It does this by outlining traditional historiography, an approach found in most total histories, and compares this to sociological and post-structuralist approaches on the critique of historical research. This approach can then be used to highlight the current gaps in historical accounts of dementia, and supports instead the need for a richer epistemological positioning and enquiry. This chapter will begin with a brief review of traditional historical research approaches. It will then introduce 'historical sociology' as an alternative approach, and then apply the principles of post-structuralism and Foucauldian analysis, particularly Michel Foucault's ideas on the history of problematization. This will support the unique contribution to the history of dementia this study will offer.

2.2 Traditional approaches to historical research

Knowledge about historical events rely on documents, paintings, sculpture, photographs, sound, and visual recordings. There is also a reliance on the work of 'other' historians. Despite historians viewing this process of discovering history as an art, not a science (McDowell, 2002), rigorous approaches to data collection are still adopted. Butterfield (1931) however argues that some historians may still organise their knowledge to fit in with a predetermined interpretation of history –

commonly referred to as 'Whig' or 'Whiggish history'. McDowell (2002) notes risks for this type of interpretation in equating history with evolution and identifying progress as a key theme. However what is commonly agreed as the task of history, is the art of re-constructing the past from documentary and other evidence available, using established and rigorous procedures; an approach commonly referred to as *historiography*.

In the 1990s increasing numbers of history degree courses in Britain and the USA included historiography in their teaching (Evans, 2000 [1997]). Ranke (1795-1886) is usually presented as the 'founding father' of the historiography approach (Arnold, 2000), and maintained historians should aim to produce a scientific and objective history. However, this concept of 'objectivity,' or, 'the sole reporting of fact,' is also not without its critiques. Carr's (1961) classical text '*What is History?'* has been widely used as an introduction to historical study (Evans, 2000 [1997]) yet challenges and undermines the belief that history is simply a matter of objective facts. He instead introduces the idea that history books, like the people who write them, are products of their own times, and that their authors bring particular ideas and ideologies to bear on the past (Carr, 1961). Evans (2000 [1997]) notes this relativistic approach by Carr challenges other previous historical approaches. Other major works on what and how to study history can be found in Elton's (1967) classical text '*The Practice of History'* (Jenkins, 1995; Evans, 2000 [1997]). Here, Elton (1967) not only argues that history is a search for the objective truth about the past, but that any serious historical work should also have a backbone narrative of political events; if it did not include this, then it was not proper history. For Elton (*ibid.*) there was a primary need to focus on the documentary record, and to dismiss the historian or their motives. Despite this sharp contrast to Carr (1961), this text has been seen as the mainstream position of the historical profession (Jenkins, 1995; La Capra, 1987; Marwick, 1989).

Other challenges to Ranke's original historiography also include Braudel (1902-1985), who argued history should move beyond mere *courte durée* (short span) or *histoire événementielle* (a history of events), and instead consider the slow and imperceptible effects of space, climate and technology on the actions of

people (Braudel, 1969 [1958]; Wallerstein, 1998 [1996]). Braudel here attempts to attack dominant practices of historians, particularly with their overt focus on 'episodic history' (Wallerstein (1998 [1996]). Braudel (1969 [1958]) argues that traditional history privileges 'time' over 'duration', and, according to Wallerstein (1998 [1996]), fought against dominant views in history that ignored structure and socioeconomic influences. Evans (2000 [1997]) for example argues historians are increasingly being compelled to address how the practice of history is studied, researched, read and written about.

Generally, traditional historical research represents a systematic enquiry into the past, separating historical accounts or events between truth and fiction. However, each generation of historians may well have its own preoccupations and values which will affect their perception of past events including,

> "What they [historians] see as significant, what they disregard, and what connections they assume between the occurrences of particular events." (McDowell, 2002:5).

What is missing is 'theory' to organise such thoughts. In effect this leaves chronology playing an important part in the explanation of historical events, whereas social scientists tend to focus on patterns and trends (McDowell, 2002). During the nineteenth century, historians almost exclusively focused their attention on political history, because this is where most of the documentary evidence was available (*ibid*). However, towards the end of the nineteenth century, historians began to shift their focus from political and constitutional history to a consideration of social and economic history, placing more emphasis on the lives of ordinary people and mass movements. The social sciences however can be distinguished from such historical research because they paid more attention to social and economic structures, functional relationships and social theories (*ibid*).

In the post-war period there has been a developing interest in the use of quantitative methods in historical research. Statements which were based on the use of quantitative data appeared more reliable and assumed a higher status than qualitative statements. However, as McDowell (2002) notes, studies which were based only on the evidence which was available and able to be quantified,

were always likely to produce an incomplete and distorted account of reality, because the statistical data still had to be interpreted. For the historians, a historical fact was something that happened in the past, which had left traces in documents which could still be used by the historian to reconstruct it in the present (Evans, 2000 [1997]). As such, and in contrast to social science approaches, Elton (1991) argued the historians questions should be formulated not by some present theory, but from the historical sources themselves.

Consequently there is a need to be mindful of the limitations of the range of historical approaches that may be entrenched in traditional historiography, and how this may then affect the published literature on the history of dementia. Thus, the history of Alzheimer's disease produces a historical narrative that tends to begin with Alzheimer's first description in 1906, and Kraeplin's naming of the disease in 1910, virtually ignoring the next five decades, before finally skipping ahead to the history of current research projects rooted in the 1970s and later (Ballenger, 2006a). Although it may be important to study the great men [and women] and how their contributions laid foundations to contemporary ideas, this approach to history oversimplifies the actual historical development of science *(ibid*). This may be resolved by turning to the social sciences when researching the history of a social phenomenon like dementia. This approach departs from mere objective fact or just those who were recorded as making the discoveries, and instead focuses our analysis on the social apparatus, historical discontinuities and ruptures, relations of power and knowledge, and disciplinary ownership. A potential way of doing this can be found in the discipline of 'historical sociology'.

2.3 Introducing 'historical sociology'

Although the relationship between sociology and history has been seen as incompatible (Popper, 1962; Rickert, 1962) a number of writers have clearly advocated the benefits. Writing in the early 1980s, Abrams for example argued;

> "In the past thirty years the gap between history and sociology appears to have narrowed dramatically." (1982:iv),

Smith (2014) noted that the hybrid discipline of *historical sociology* draws not only on sociology and history, but also on anthropology, international relations, political studies and social theory. Interestingly, Abrams (1982) suggests that many of the most serious problems faced by sociologists need to be solved historically, adding too that;

> "... [The] shaping of action by structure and transforming of structure by action both occur as processes in time. It is by seizing on that idea that history and sociology merge and that sociology becomes capable of answering our urgent questions about why the world is as it is; about why particular men and women make the particular choices they do and why they succeed or fail in their projects." (1982:3)

Historical sociology thus is the attempt to understand the relationship of personal activity and experience on one hand, and social organisation on the other, something that is continuously constructed in time. It is this continuous process of construction that becomes the focal concern of social analysis (Abrams, 1982). For the problematization of dementia this is an important consideration. Dominant constructions of dementia are located across several sociological spheres, powerfully sustained through their being able to produce an image of dementia in society (Davis, 2004). Historical sociology is part of one such sociological sphere, although to date has paid little attention to dementia. Sociologists who adopt historical analysis in their research, are however numerous. Classical examples of such approaches include: Marx (1976) *Capital: A Critique of Political Economy*; Durkheim (1879) *Suicide: A Study in Sociology*; Weber (1930) *The Protestant Ethic and the Spirit of Capitalism*; and, Foucault (1973 [1963]) *The Birth of the Clinic: An Archaeology of Medical Perception; Discipline and Punish: The Birth of the Prison* (1977 [1975]); *Madness and Civilisation: a history of insanity in the age of reason* (1967 [1961]).

The last of these, Foucault, did not actually describe himself as a sociologist, largely evading any neat labelling that would place him in any particular discipline (Hamilton, 1985). However his approach and impact on social analysis has been of such significance to sociology, that writers such as Smart (1985) have come

to see him as a key sociologist in his own right. Foucault's approach (sometimes referred to as 'Foucauldian Analysis') is associated with post-structuralism, a key theoretical development in the subtler interpretation and critique of history (see Attridge, *et al.,* 1987). This approach, missing in the most part from many published accounts on the history of dementia, would no-doubt prove a useful addition to extending our knowledge in this area.

2.4 Post-structuralism, Foucauldian analysis, and the question of history

Post-structuralism is a theoretical paradigm based on a particular way of looking at, conceptualising, and interpreting the world. It includes a group of theories concerning the relationship between human beings and the world, and, importantly, the practice of making and reproducing meaning (Belsey, 2002). Integral to post-structuralism is its suspicion of any apparent ease with which a subject is 'decentred' by the systems in which they interact (Bennington and Young, 1987), a latent construct of structuralism, from which post-structuralism now departs. Central to this departure is the rejection of the notion that ideas are the source of language with instead arguing that ideas actually become the effects of meaning. Here, meaning is essentially differential, not referential to ideas and concepts; an important consideration when looking at how dementia has come to be conceptualised.

Although both paradigms (structuralism and post-structuralism) consider the question of history, they do this in different ways. Structuralists, in particular, are accused of omitting history (Lévi-Strauss, 1968; De George and De George, 1972), despite some limited occasion to work collaboratively with this discipline (see Attridge, *et al.,* 1987). Post-structuralists however argue that we can never know the *true meaning* or the 'real', as there may be many truths 'out there', and that it happened (or rather what they say happened) will always be biased, either consciously or subconsciously. Thus any given interpretation is only one example of many 'other' interpretations, in this context, is therefore unknowable because

it is just a construction. Thus it wasn't waiting to be found for example as discourse within a document, because the document is a product through a social apparatus that allows and legitimates its authority. What we have been left is only what we know now from traditional historiography; dominant and largely unquestionable perspectives. The so far presented histories of dementia can only be seen as a history of the dominant discourse, rendering it partial and incomplete.

Using then Foucault's exposition of the contingent formulation of disease, and the corresponding problematization of dementia (Davis, 2004), preparation can be made for an exposition of the related literature. Importantly, whilst using a post-structuralism approach is beneficial, it can also prove a little confusing. This is because Foucault, argued by many to follow a post-structuralist tradition, may be better described as a 'historian of thought' and it is this on this latter point that much of this study will centre - a history of thought about the problematization of dementia in Western society.

Importantly, considering Foucault's general methodological approach, which he called 'archaeology', we find a particular historical approach distinguishable from historiography. Rather than focusing on developments over specific periods of time, looking for the progress of consciousness, teleology of reason or evolution of thought (Foucault, 1972 [1969]), discontinuities and ruptures instead become the looked for. For Foucault, this involved a detailed examination of the conditions of possibility in which particular systems of knowledge and discourse take place. Changes in dementia conceptualisation need to be found, understood, and then reviewed in terms of the social apparatus or systems of thought in operation at the time.

However Foucault also suggests that such analysis must also move beyond these basic points as on their own they provide an inadequate response (Foucault, 1989b). This led him to question:

> "What else was it that I was talking about... but power? (Foucault, 1980:115)

Foucault then began to turn his attention to also consider a dynamic link between knowledge and discourse with 'power' (Foucault, 1989c; 1991) and introduced the concept of 'genealogy' (Foucault, 1977 [1975]; 1978 [1976]). Foucault's genealogy of Western pathological medicine for example looks back, historically and culturally, to the scientific climate of the end of the eighteenth century (the focus of his own historical research). His own critique focuses on the 'anatomo-clinical gaze' that emerges as a radical shift in the discursive practice of medicine after the Enlightenment (Davis, 2004). Thus the conditions of possibility for the emergence of the gaze depended on the increasingly technical medical perception that arose from underlying societal structures. For Foucault, the production of such knowledge reveals more fundamental epistemological structures of a given moment of discursive formation (Davis, 2004). He views scientific understanding, its epistemology, as sanctioning a certain representation of reality, a 'will to know' (Foucault, 1978 [1976]) and that this, *a priori*, allows for the historical possibility of a particular legislative medical project. Foucault is thus showing "how effects of truth are produced within discourses that are in themselves neither true nor false" (Foucault, 1980: 118).

This is an important statement for it questions what we actually mean by 'truth' when conceptualising dementia, as there is no thing as truth, and so any found discourse can be neither true nor false; justifying the search for alternative conceptualisations. With this in mind, the phenomenon of dementia can be examined through the gaze (a specific way of seeing dementia) in a multiplicity of ways. This may be through the formations of knowledge predicated on the established discourse as generated by any one particular episteme. Thus any review of the dementia literature needs to look out for revised designations of dementia that show how this disease-category has come to authorise certain socio-cultural norms.

The social influences that have framed the present history of dementia need to be considered. For Foucault, this examination of the history is then one of problematization (Foucault, 1984), and history of dementia should essentially be how the condition has come to be problematized (Davis, 2004). In establishing

for example that dementia was previously regarded as a normal part of ageing (Gubrium, 1986), and that the advent of rationalist modes of investigating the condition has led to its problematization as a neuro-psychiatric condition (Downs *et al.,* 2006), the phenomenon of dementia thus becomes inescapably embedded in social discourse. In particular this discourse portrays two very different conceptualisations of dementia – the *normal* and the *pathological*. Just how far current histories of dementia recognise this is essential.

The rationale for this study then is to emphasise and then examine this 'general history of dementia' (the differences, transformations, ruptures, continuities and discontinuities that have taken place in how dementia has been conceptualised). This approach is in direct contrast to 'total histories of dementia' that instead suggest a totalistic form of conceptual transformation divided by cohesive periods and based on the scientific discoveries of the time.

Chapter 3: Literature Review

3.1 Background to the literature review

The history of dementia follows the development of its conceptualisation as a neuro-psychiatric disorder, defined, diagnosed, assessed and managed largely within the field of old age psychiatry (Downs, *et al.,* 2006). Contemporary views on this condition continue to maintain its construction as a biomedical disease (WHO, 1992; NICE/SCIE 2006; APA, 2013). However as Innes (2009) notes, such biomedical constructions, including definitions provided by the WHO (2001) (cited by Innes, 2009:4) and the Alzheimer's Society (2006) (cited *ibid.*) hide the knowledge generation that underpins these definitions and create, in effect, acceptance of the medical model. Exploring this knowledge generation and the 'conceptualisation of dementia' throughout history thus becomes an important goal in our understanding of this disease. How far current knowledge portrays either 'general' or 'total' histories becomes an important consideration of this.

It has been argued that any systematic study should map the changes in history of dementia at least since Roman times (Berrios, 2010). Additionally, it should also include reference to the main debates in the history of AD, such as its differentiation from senile dementia, the effect of arteriosclerosis as a main cause, and if either senile dementia or AD are inevitable consequences of ageing (Beach, 1987). A need to consider how dementia 'became known', its subtypes, and the history of subtypes other than AD, as well as the overt focus on AD (see Ballenger, 2006b; Lock, 2013; Whitehouse, *et al.,* 2000) should also be understood.

The aim of this chapter is to provide a review of the published history of dementia whilst also taking into account the above considerations as part of a carefully considered critique in teasing out any gaps and omissions that warrant a further detailed enquiry into how dementia is conceptualised in Western society.

3.2 Searching the literature

Details of the criteria for inclusion and search strategy are shown in Appendix 1 'Search Statement Grid'. Keywords are divided into Set 1 (dementia) and Set 2 (history). In Set 1, due to both the complexity and heterogeneity of the 'umbrella' term *Dementia* (Knifton, 2009), keywords were used that included *Dementia* or *Alzheimer's* or *Senility.* As most forms of dementia include the word dementia somewhere in its title (Dementia with Lewy bodies, vascular dementia, frontotemporal lobe dementia) it was envisaged that this term will include these common forms of dementia in Western society (although it is recognised some of the rarer forms may not be picked up). This however also may fail to pick up Alzheimer's disease so this latter sub-type was used as a separate term and additional search strategy. Senility was also considered a valid search term based on the early confusion in reported texts between senility and dementia. In Set 2, the term 'history' within the title of the work was considered. However, the keyword *history* was represented by a descriptive typology, rather than a single definition, given the broad scope of data capture that the systematic review would be designed to cover. Thus alternative words used as part of this descriptive typology included both *history*, and definition*, concept, terminology, construction, origins and medicalisation*. To ensure inclusivity in both sets of data, where appropriate, search terms included truncation to allow for word adaptations (for example 'concept' was truncated to 'concept*' to include 'concept, concepts, conceptual, conceptualisation, conceptualization', etc.). In addition, exclusion criteria for each Set was used in order to remove inappropriate articles (for example, exclusion of all articles with reference to the full term 'dementia praecox' as this was the term originally used to describe schizophrenia in Set 1); for each search term the full exclusion criteria is shown in appendix 1.

It is important to note that a language restriction was also set. Only articles available in English were considered. It is important to note that this led to some articles being excluded (Matusevich, 2009, *'The social construction of dementia: an hypostudy'* – article only available in Spanish), unless accompanied by an English translation (such as that written by Burchynsky, 1998, *'Problems of*

dementia: the history of formation of ideas about the nature of Alzheimer's disease' originally published in Ukrainian and Russian, but with English translation). No date exclusions or parameters were selected due to the historical discussions being searched for.

Electronic searches were performed using the above criteria through search engines commonly used amongst researchers in psychiatry, medicine, and health and social sciences. The date span/coverage for each database is included in brackets: BNI (1994 – 2014), Medline (1946-2014), CINAHL Plus (1937-2014), PsycARTICLES (1894-2014) and PsycINFO (1887-2014). A search of the published literature was initially carried out up to 1st April 2014, the time of the writing the literature review chapter (see appendix 1 'Literature Search Inclusion'). However as this search ended in 2014, and the overall study was not completed until 2018, four years later, the effect this would have on the authenticity and credibility of the study was considered. Consequently, a second search of the literature was carried out as the study neared its final completion. The same search techniques and databases were used (noting the only difference being BNI re-termed as BND [British Nursing Database]), with the date range April 2014 to 2019. This resulted in an additional 14 published papers (Dening and Sandilyan, 2015; Engelhardt and Grinberg, 2015; Hilton, 2015; Ingram, 2014; Ohry and Buda, 2015; Vinters, 2015; Woll, 2016; Ballenger, 2017; McKay and Counts, 2017; Mueller, *et al.,* 2017; Jebelli, 2018; Jellinger, 2018; Keuck, 2018, and Papavramidou, 2018). These were added to the literature review findings.

Following the literature search for journal articles, a manual search was also carried out to identify key texts usually in the form of academic/clinical textbooks. There is little research on the validity and reliability of using such examples as part of a systematic literature review although their exclusion would limit the data range. In terms of the topic (history of dementia), it was felt a necessary inclusion. The manual search specifically included books and/or book chapters relating to the same subject areas as noted in set 1 and set 2 above. This was performed through browsing library catalogues and reviewing chapter headings in dementia

or psychiatry textbooks (Berrios, 1995a; 2010; Kitwood, 1995; Porter, 1995), reviewing the reference/ bibliographic pages of the many of the articles selected above (Harding and Palfrey, 1997; Torack, 1983), published book reviews containing the same key words in set 1 and 2 (Ballenger, 2006b; Harding and Palfrey, 1997; Whitehouse, *et al.,* 2000) and expert advice from the supervisory team (Lock, 2013), where indicated.

Study selection

Articles and books/book chapters were assessed if they met the inclusion criteria on the basis of titles and abstracts, and in the case of books/book chapters, on the basis of published book reviews and preface/introductory chapter reading. Full papers and hard copies of all books were obtained for all relevant studies. This concluded published studies spanning from 1907 to 2018. These works are depicted at the end of appendix 1.

Data extraction

Historical claims concerning the emergence of the concept of dementia became the primary aim. Each claim was reviewed on the evidence used to generate its validity (such as reference to primary or secondary data), and the historical dates covered. Data was also extracted on whether reference was made to cultural, political or social constructions of dementia and how this may affect interpretation. Distinguishing between the 'term' and 'concept' of dementia in historical analysis was also an important theme, and as such including consideration for changes in use of the word 'dementia', different types of terms adopted (e.g. *morosis* and *dotage*), recognition or unawareness of differential diagnosis, and relationship between 'senility' and old age. Finally, analysis of the type/form of dementia, where this was given was considered.

Assessment of quality

Assessment of the quality of the published work was based on reference to original materials. This was an important consideration as some papers referred almost solely on the completed historical accounts of others, whilst others sought to locate the original documents themselves. Consideration was also given to the date of publication and the technological advances at the time. This is an important consideration given that the earliest article referred to was published in 1907. An understanding of the authorship was also necessary to differentiate historical accounts being written by historians (such as Ballenger, 2006a; 2006b), anthropologists (Lock, 2013), archaeologists, sociologists, theologians, psychiatrists, philosophers, psychologists, neurologists (Whitehouse, 2000), and so forth – each discipline potentially having their own academic perspective/ research paradigm and thus potential bias, although equally important is not to presume a bias exists based on the authors profession.

A second method of assessing for quality was to compare/contrast the histories as presented by differing authors. Examples of consistency in this sense would be seen positively. Where discrepancies arose then the papers could be checked for how they substantiate their claims – what is their evidence. In addition evidence for various published 'histories' relying on similar source material, again particularly where there was a high degree of consistency, could also be reviewed so as the quality of this source could also be examined as part of the overall critique. All the papers for example might all be referring to the same one piece of evidence to make their claim, but when examined this evidence was of poor quality. This would then negate the presumption as made earlier that consistency was 'always' a sign that accurate conclusions could be made.

3.3 The recorded history of dementia

Based on the above criteria and subsequent analysis, writings on the history of dementia were found spanning an historical time frame between 2000 BCE to 2010 CE, some 4000 years. To follow is a brief summary of the consequent meta-analysis of these 65 published 'histories' together with commentary. For the reader's convenience, and to sort the data and provide a degree of historical perspective, this has been organised into seven specific time periods: Early ideas on dementia – circa 2000 BCE -25 BCE; Early ideas on dementia – circa 50 CE – Sixteenth century; Seventeenth/Eighteenth centuries; Nineteenth century; Twentieth century; and finally the Twenty-First century. Following these discussions, these works, which are largely based on historiography (with a few exceptions), will be summarised before a concluding critique is given to support the need for further sociological, and specifically post-structural research in this same area and thus to support the unique contribution this study can make to the already published discourse on the subject. A summary of the main historical findings as cited by authors from our searches of the literature are presented in appendix 2. This is presented in chronological order, with a brief statement regarding the historical finding (such as a particular scientific discovery or noted clinical finding), and the names of the authors from our literature review who have cited this as being important in the history of dementia. Appendix 2 is used in this case as a quick list to show the main historical events, some of which are discussed more fully below, ordered by date with citing author, and thus, is used to summarize or complement this chapters findings.

Early ideas on dementia – circa 2000 BCE – 25 BCE

The beginnings of the concept of dementia, or its phenomenology, has been traced as far back as the ancient Egyptians, from the time of 2000 BCE, based on the suggestion that memory disorders were known to accompany older age (Boller, 2008; Boller and Forbes, 1998; George, *et al.,* 2011b). And, as Loeb (1995) in particular notes, the *Ebers Papyrus* of 1500 BCE also contains a brief

mention of senile deterioration. In these works we see the conceptualisation of old age mental decline, leading these authors to refer to such ontological thinking as the earliest documented reference points possibly to dementia, although importantly noting that at this time that memory loss and decline was not seen as a separate category of disease (dementia), but rather as a natural part or consequence of ageing, an important point when considering conceptualisation.

The focus for many of these depictions that are cited focus on the principle of memory deterioration, although the understanding of this is not so forthcoming. Indeed much of the literature seems to suggest this frame of reference in being so commonly used, may not warrant further exploration or interrogation. The focus on 'memory' however does need further consideration. Additional symptomology, such as decline in activities of daily living, and behavioural and psychological symptoms seem to be disregarded, or at least under-represented in such reports. Memory decline, although a common feature of dementia, may also exist in a range of other common disorders. Distinguishing between disorders in this way is commonly referred to as 'differential diagnosis' and would include as some possible examples, depression, delirium, or even hypothyroidism. Although this concept and understanding of disease processes would have been absent from the original text, these types of disorders would still have been grouped under senile deterioration, and thus any history of dementia in recounting these original works needs to recognise this potential blurring in their analysis. The early history of dementia thus cannot be used simply to equate memory loss as the starting point of its conceptualisation. This could only be considered if it is made clear that this is done only in the absence of any clinically recognised disorder, where a range of symptoms noted in the older person affect overall activities and practices, and this then is what it is to be old. This becomes the initial conceptualisation.

However, one of the earliest theorists to provide discussion on what we today might understand or consider as a dementia, is argued to be found in the work of Pythagoras (Berchtold and Cotman, 1998; Fukui, 2014; Papavramidou, 2018) in the sixth/seventh century BCE. Here he argued when people reached the

‘senium’ (defined as over 63 years of age), it would be characterised by derangement (Papavramidou, 2018), imbecility, or decay of the mental capacities (Fukui, 2014). This conceptualisation appears to have continued for over a century where Vannoy and Greene (1989) note, in ‘Solomon’s Law’, written in 500 BCE, and with a clear reference to senile or old age mental deficiency that;

> “...provided that his judgement was not influenced by physical pain, violence, drugs, old age, or the persuasion of a woman.” (Cited by Vannoy and Greene, 1989:15).

Solomon was a Greek lawmaker and Athenian judge who revised the practice of family inheritance. The importance of Solomon's or (Solons Law as it is sometimes called) has been noted by a number of authors (Berchtold and Cotman, 1998; Boller, 2008; Boller and Forbes, 1998; Brannon, 1994; Cassanova, *et al.,* 1998; George, *et, al.*, 2011b; Papavramidou, 2018) studying the history of dementia. For some writers (Fox, 1989) this was the earliest reference to dementia associated with ageing. We need however to recognise that this passage is taken from Solomon’s revision of the making of wills and the practice of dividing inheritance within the family, with the above being seen as a qualification to potentially invalidate a will. The power and politics at the time go largely un-discussed by a number of these authors and there is no mention here of the considerable esteem largely bestowed on elderly family members and the dynamic of power and the effect this would have had on the largely agrarian, landowning Greek population, a point seemingly only considered later by Torack (1983).

Interestingly, Torack (1983) also notes that Hippocrates (460 – 370 BC) makes no mention of ‘incompetent behaviours’ or mental decline in the elderly when he discussed his many mental disorders, probably because senile dementia was considered a normal and routine part of ageing. Again this is important for it hints at an important conceptualisation of dementia but remains so in only a partial way as it neglects any clear account of the systems of knowledge that may allow for this type of reasoning existing in the first place. However, Hippocrates did argue that ‘paranoia’ represented the deterioration of mental faculties in the state of old age (Berchtold and Cotman, 1998; Fukui, 2014) but why this was considered

symptomatic of ageing and not part of a separate mental disorder needs further consideration. Interestingly, despite making reference to numerous mental derangements (Papavramidou, 2018), Hippocrates did not include nor refer to mental decline in old age, or dementia in advanced age, amongst his inventory of mental disorders (Fox, 1989). This was argued to be because this was considered to be a normal part of the ageing process at this time (Torack, 1983).

In 380 BCE, Plato's principle document *Republic* also supports reference to mental deterioration in old age (Berchtold and Cotman, 1998; Boller and Forbes, 1998; Fukui, 2014; Porter, 1995; Brannon, 1994), with some writers (see Torack, 1983) suggesting this to be a clear recognition of what we today refer to as 'senile dementia'. Here, Plato importantly argued that mental deterioration was inseparable from old age, and also is cited as arguing;

> "The commission of certain crimes (sacrilege, treachery, treason) is excusable in a state of madness or when affected by disease or under the influence of extreme old age or in a fit of childish wantonness." (Cited by Torack, 1983:23)

Dementia associated with old age at this time was a possible excuse for some crimes. A further common feature of these early historical ideas is the continued association between dementia and 'natural' ageing. This association is further supported when coupling Plato's thoughts on bitter and bilious humors trapped in the body that lead to forgetfulness with Aristotle's work on cold black bile associated with old age (Papavramidou, 2018). Here, Aristotle also began to argue old age as associated with deterioration, caused by dullness, and as the mind deteriorates there is no memory nor sentiment of love (Hicks, 1907; cited by Papavramidou, 2018: 2012).

This notion continues into the Roman Period when the word 'dementia' was used to mean being out of one's mind, a synonym for madness (Berrios, 1987; 1995a; 2010) commonly associated with age-related decline. This is in contrast to the world of Solomon where the elderly were held in high esteem. Torack (1983) also argues that Rome was rapidly changing and the elderly were instead largely vilified. This can be seen in the writings of Horace in *Ars Poetica,* who, in describing the characteristics of old men, argued:

> "Desire for gain, miserliness, lack of energy, quarrelsome, praise of the good old days and a condemnation of the younger generation." (Horace, cited by Torack, 1983:24)

This idea however was also open to challenge, such as seen in the work of Cicero (106 BCE – 43 BCE) in *De Senectute*:

> "As wantonness and licentious are faults of the young rather than of the old, yet not of all young men but only of the depraved, so the senile folly called dotage is characteristic not of all old men but only of the frivolous." (Cicero, cited by Torack, 1984:24)

The latter sentence in Cicero's work cited above is important: 'characteristic not of all old men'. This clearly recognises that old age did not always mean mental decline (Berchtold and Cotman, 1998; Fukui, 2014; Loeb, 1995; Blumer, 1907; Berrios, 2010), and that dementia was therefore used as a synonym of madness and not of ageing. This important observation is to be seen as a clear attempt to separate mental decline from solely old age. This represents a change in the discourse in how it was to speak both of an older person and also of dementia. It reflects a discontinuity or rupture in the systems of thought and knowledge at the time, suggesting sociological influences may have framed the presented early histories *construction* of the concept of dementia. However any attempt to provide a critical and detailed discussion of this appears unrealised in most of the traditional histories of this subject. This is important because an examination of the history of thought, (including the conceptualisation of dementia) is one specifically of problematization (Foucault, 1984). However in such traditional histories we are rather presented with what appears as an account or a teleology of reason. In establishing that dominant discourse 'created' (and as we will see later, preserved) the idea of dementia as a normal part of ageing, despite the availability of an alternative discourse situating it as a mental disorder, leaves it inescapably embedded in a potential sociological discourse. Attempts at providing such a sociological discourse are although generally lacking

Early ideas on dementia – circa 50 CE – Sixteenth century

Three hundred years later, two early writers of the second century BCE, Galen and Cicero, believed that the seat of the soul was in the brain. This led to attempts in distinguishing between diseases of the body from those of the soul (Loeb, 1995). It is within this system of thought that Cicero provided the term 'dotage', indicating senile debility (Fukui, 2014). Galen, on the other hand used the term 'morosis' (Fox, 1989), listing old age as when it may occur and identified it as a mental disease (Berchtold and Cotman, 1998; Brannon, 1994; Cipriani, *et al.* 2011; Fukui, 2014; Loeb, 1995; Schwartz and Stark, 1992). He in particular noted in his definition of morosis;

> "Some in whom the knowledge of letters and other arts are totally obliterated; indeed they can't remember their own names... Even now it is seen, that on account of extreme debility in old age, some are afflicted with similar symptoms." (Galen, cited by Torack, 1983:24)

Importantly little consideration is however given to Galen's attempt to separate mental deterioration from old age, and the similarities between this discourse and that presented earlier by Cicero are thus of sociological interest. Although some historical writers note its connection to old age (See Torack, 1983) his use of language could also be argued to suggest he is merely making a comparison rather than suggesting they were one and the same. It is more likely that Galen is suggesting dementia although common in old age was still, in its own right, considered a medical disease. Galen was thus first to suggest that the association between morosis (dementia) and old age is co-incidental and that old age is just one of the situations in which it may occur. Again this is an important deviation from dominant earlier perspectives and adds to the growing discourse on the conceptualisation that dementia is as a natural consequence of ageing or a specific disorder.

Introduction of the actual term 'dementia' however is attributed to the work of Celsus, known as a Roman medic writing in the first century CE (Vannoy and Greene, 1989) in his work *'De Medicina'* (Cohen, 1983; Fox, 1989; Porter, 1995).

It is important to note that here we speak of dementia as a term and not yet as a concept.

Following the decline in the Roman Empire in the fourth century CE, scientific research declined as greater concern was given to the teachings of the Church's doctrine (Fukui, 2014). Indeed before the late 1800s dementia was thus thought to be caused by a range of moral or religious factors (Whitehouse, 2000). However the Church's teaching on dementia, or even age-related mental decline has been less researched by historians of dementia and consequently there are few if any published discussions of what this may have included.

Thus, during this early period the literature seems to suggest that there were possibly three different ways of conceptualising dementia (as a natural consequence of ageing, an unexplored church/religious teaching idea, and finally as a disorder of some type). Despite support for alternatives, one dominant view appears – dementia as a natural consequence of ageing. Reasons for this dominant discourse including the conditions of possibility that allow one idea over another to take form and become dominant, have so far been largely ignored in the literature.

Seventeenth/eighteenth centuries

Despite arguments that the historical notion of dementia was relatively scant up until the first half of the nineteenth century (Loeb, 1995) some writers have provided discussion. Fox (1989) for example notes that during the sixteenth, seventeenth and eighteenth centuries, notions of what we now could call senile dementia, including dulling of senses, failing judgement and the return to a childlike state, could be found in the writings of medical practitioners. However, the first recognised use of the concept (rather than the term as noted earlier in this chapter) as we now understand it, particularly within a clinico-pathology sensibility, can be traced back to the work of Willis in 1684 (Berrios, 1995b; 2010). It also appeared amidst a range of European vernaculars as found in the Oxford English Dictionary of 1644, Blanchard's 1726 dictionary, and a Spanish-French

dictionary of 1791 (Sachdev, 2000; Berrios, 2010). However what can be described as the 'medicalisation of the term' did not appear until after the 1750s (see Berrios, 1995b; Sachdev, 2000). The earliest medical usage of the term however can in fact be found in a French Encyclopaedia by Diderot and d'Alembert in 1765 (Berrios, 2010). Interestingly Berrios (2010) is clear to point out that these definitions must be read with caution as they need to be contrasted with conditions that no longer exist. Thus, behaviours that we now refer to as dementia may have in the past been referred to under different headings as seen in the works of Bossier de Sauvages' 1771 work on Nosographie Methodique, and Pinel's 1806 Nosographie (pp. 6-7). What is of interest is that Berrios (1990a) notes that at this time, the term 'dementia' did not necessarily evoke an association with old age either. A useful example of this, he notes, is the use of the term *'dementia praecox'* – which is not a form of dementia as we now know it today, it is rather a term for what we now call schizophrenia.

Alternative examples of this can also be considered within the work of Willis who did not actually use the term 'dementia,' and rather reference to the idea of dementia is found through his concept of 'stupidity and foolishness' (Berrios, 1995b). This application may not be though so straightforward. This is particularly noticeable if one considers association of 'stupidity' with 'learning disability'. However Berrios (1995b) is careful to read further into the original text to clarify the term was also applied to those whose condition was caused through ageing or stroke, linking the term to dementia. What this may suggest is a potential mixing between mental disorder and disability, with little separation between learning disability and dementia. This is an important consideration when looking at possible different systems of thought and their histories that may intersect before running their separate paths. Here then the relationship between the history of dementia and the history of learning disability is of interest but has not yet been explored.

For some writers (see Torack, 1983) the work of Pinel however is particularly significant as he is attributed with coining the term 'démence', although as we

have already found he was not actually the first (see Diderot and d'Alembert in 1765).

Nineteenth century

By the turn of the nineteenth century, Pinel also asserted that because no organic lesions could be seen in the brain, mental illness had no organic origins (Lock, 2013). This is important because still during the nineteenth century dementia referred to a largely irreversible cognitive state, largely affecting the elderly but was starting to gain recognition as a mental disorder. Important in establishing dementia as a recognisable mental disorder was the work of Esquirol, who through his 1805 doctoral study attempted to distinguish between acute, chronic and senile dementia (Berrios, 2010). Although the term 'dementia' was already in use by this time, the more specific term of 'senile dementia' wasn't, and its first usage is thus attributed to Esquirol (Fox, 1989). However it is important to note that Esquirol, together with his student Georget, supported a descriptive approach to mental disorders, affecting any subsequent classification. In their 15 dementia cases the mean age was only 34 years, thus clearly suggesting that age was not an important variable for dementia (Berrios, 2010). This is an interesting finding as it questions the notion of dementia exclusively linked to senile decline, which was still a common belief held at this time and a clear example of discontinuity in thought. Arguably this is an important point for Esquirol who clearly saw a particular need to create a specific category of 'senile dementia' suggesting dementia in other life stages other than in the senium were in existence.

In the year 1857, a cause for insanity was found; general paresis was connected to a syphilitic infection (Ballenger, 2017), importantly what also later became termed neuro-syphilis dementia or dementia paralytica. This became the first mental disorder to have a clear pathological basis. However more fundamental was the idea that other mental disorders too could be linked to a clinico-pathology. Importantly the continued use of the term senile dementia was adopted by Alzheimer in his 1894 paper [Dementia senilis, senile Demenz], as well as in his later work although he remained concerned there was a paucity in

clinicopathological studies when compared to the abundance on dementia paralytica (Engelhardt and Grinberg, 2015). This was important as psychiatry was viewed as falling behind other areas of medicine which were fast progressing in terms of identifying disease pathology (Rosenberg, 1992b). Later, in 1860, Morel developed a taxonomy of causes of mental disorder, suggesting six groups, the latter of which he called 'dementia' (Berrios, 2010). Based on degenerationist theory this became once again associated with ageing and decline and importantly conflicts with Esquirol's research. This theory focuses rather on the ideas of cell-degeneration in senescence, based on the work of Schwann and Virchow (1858) who confirmed the ideas of tissue degeneration. This led to the development of ideas that ageing itself was a medical problem due to the inevitable deterioration of tissue and cells (Haber, 1983). Of interest is also the discontinuity presented here, a potential rupture in systems of thought that has been given little attention by historians, including how this earlier research by Esquirol became effectively subjugated and ignored. From all the historical accounts mentioning Esquirol, only Berrios (2010) mentions this work although does not reveal in any detail the potential importance of a suppressed discourse.

As Esquirol is noted to have introduced the term 'senile dementia', over a decade later the term 'pre-senile dementia' (dementia occurring in people under the age of 65 years) was coined by Binswanger in 1868 (Cohen, 1983). This importantly marked a surge of interest to distinguish dementia from natural ageing, (something Esquirol rather unsuccessfully had tried), and by the latter half of the nineteenth century different forms of dementia grew in notoriety, although we were still some time from referring to them in the way we do today as dementia sub-types. These different forms did however include 'general paralysis of the insane' (now called dementia paralyticia or neurosyphilis dementia), the vesanic dementias (which in many cases may be likened to current interpretations of delirium), arteriosclerotic dementia, apoplectic dementia, Alzheimer's disease, and the frontal dementias (Berrios, 2010). To understand this found range of dementias and of each their own historical 'discovery' is then also of clear interest, yet remarkably this is overlooked as many histories appear to focus predominantly on the discovery of Alzheimer's disease (see Ballenger, 2006a;

Lock, 2013; Whitehouse, *et al.,* 2000). Exceptions to this however have included senile dementia (Amaducci, *et al.,* 1986; Engelhardt and Grinberg, 2015, Halpert, 1983; Kassel, 1965; Kotsovsky, 1929; Ohry and Buda, 2015; Schwartz, 1992; Torack, 1983), vascular dementia (Loeb, 1995; Mckay and Counts, 2017; Román, 1999, 2003), dementia with Lewy bodies (Mueller, *et al.,* 2017), and uncommon causes of dementia (Förstl, 2005). This lack of historical review in comparison to other dementia sub-types with the abundance of studies on the history of Alzheimer's disease is noteworthy in our critique.

By the end of the nineteenth century, Berrios (1990) notes that use of the term 'dementia' was then being applied to name any state of psychological dilapidation associated with chronic brain disease. Here it had become a term that including a heterogeneous range of conditions including general paralysis, melancholia, mania, senile dementia, psychic disorders of the senium and vascular brain diseases (Engelhardt and Grinberg, 2015). What is clear as already discussed above, is that when it occurred in the elderly it was called 'senile dementia', and when under 65 years of age, 'pre-senile dementia'.

Twentieth Century

Arguably one of the biggest 'discoveries' in the twentieth century in the history of dementia was the discovery of Alzheimer's disease. Alzheimer could only have first described neuro-fibrillary tangles after new laboratory techniques including staining, techniques for handling the brain at autopsy, and examination of tissue blocks from different areas of the nervous system (Amaducci, *et al.,* 1986) were made available. Importantly, as a psychiatrist-neuropathologist, he ran his microscopy laboratory at the time his discoveries were made in Kraeplin's clinic (Keuck, 2018). In 1907, he went on to describe the clinical and pathological features of a case of dementia starting at age 51 (Amaducci, *et al.,* 1986:1497), with this description of characteristic clinical and neuropathological findings leading to the disease we know of today (Fox, 1989). His publication, translated as *A Characteristic Disease of the Cerebral Cortex,* and subsequent publications

by Bonfiglio (1908), Perusini (1909) and Alzheimer (1911) are argued by Maurer *et al.,* (2000) and Ohry and Buda, (2015) to have led to the eponym 'Alzheimer's Disease'. However, at the same time, publications including that of Sarteschi (1909), were also reporting similar cases. Alzheimer was the first to recognise that in this form of dementia there was also glial proliferation and a total absence of vessel infiltration. This idea importantly separated the pathological features of this newly recognised disease from those of syphilis (Amaducci, *et al.,* 1986). He was not alone in describing these cases (Ohry and Buda, 2015). Despite this, Alzheimer is often regarded as providing the first unified description of the disease (Ballenger, 2006a), deserving of this eponym for the disease that carries his name. What is less discussed is how this newly discovered clinico-pathology led to a new form of 'pre-senile' dementia, and importantly how this then changed in later years to instead refer to the opposite being the most common form of 'senile' dementia. Questions need to be asked as to how and why this change in conceptualisation of Alzheimer's disease could have taken place.

However what the literature does tell us is that a key development at this time was an apparent need to separate pre-senile from senile dementia. Amaducci *et al.,* (1986) suggests that this may be likely due to the competition between the two neuropathological schools at the time based in Munich and Prague. This would then have driven the need to name the disease. This is an important point that requires more detailed explaining for most historiographies fail to consider the systems of knowledge that led to these accounts. If indeed these two conditions were seen (as they are now) as one in the same disease characterised by neurofibrillary tangles and senile plaques, Amaducci *et al.,* (1986) argues a rivalry for the eponym may have existed between Alzheimer (who noted the Neurofibrillary tangles) and Fischer (who noted the senile plaques) (Ohry and Buda, 2015). Scientific rivalry and nosological uncertainty between the two neuropathological schools cannot be underestimated. However any controversy was settled by Kraepelin, one of the foremost organic psychiatrists of the time (Fox, 1989) arguably to the advantage of his own school, when he formally named the disease 'Alzheimer's disease' [Alzheimersche krankheit] (Ohry and Buda, 2015) in the 1910 eighth edition of his renowned textbook '*Psychiatrie: ein*

Lehrbuch für Studierende und Ärzte' (Keuck, 2018). Importantly, Amaducci *et al.,* (1986) argue that it was Kraepelin who decided to classify this as a distinct disease, separate from senile dementia, much against the thinking of Alzheimer himself. However this viewpoint has been debated (see Fox, 1989) who rather asserts that Alzheimer did in fact consider his case may have been a distinct entity and not an example of senile dementia. Here a clear and specific clinical distinction was made between a presenile (Alzheimer's disease) and a senile form of dementia (Amaducci, *et al.,* 1986), albeit based on a limited number of cases. This distinction between senile dementia and Alzheimer's disease is an important one, and one which occurs frequently in the history of the disease (see Ballenger, 2017; Barrett, 1913; Fuller and Klopp, 1912; Schnitzler, 1911). This occurred as Fox (1989) notes because of contentions as to whether the characteristic features represented a distinct disease process or not. Importantly here it has also been argued that Kraepelin (1910) and Alzheimer (1911) still referred to them as 'peculiar cases' and there was some discussion as to whether this should indicate an atypical form of senile dementia rather than an exemplar of a specific disease in its own right (Keuck, 2018). This important but under realised debate aside, Alzheimer and Kraepelin are usually seen as founders of the modern concept of Alzheimer's disease (Ballenger, 2006a; Ohry and Buda, 2015), and the term Alzheimer's disease became then only to be used to refer to dementia in younger people or pre-senile dementia (Hilton, 2015). However, what is less understood and neglected in many historical accounts is that Alzheimer's initial report drew neither little if any reaction when it was first presented in 1906, nor its publication a year later in 1907. In fact, after Alzheimer's untimely and early death in 1915, very few if any tributes to him by his colleagues mentioned Alzheimer's disease (Ballenger, 2017). Ballenger (2006a) notes that the apparent insignificance of Alzheimer's disease to Alzheimer and his contemporaries is easier to understand when put in its historical context. This concern was the need to locate psychiatry with clinical pathology. At this time, only one mental disorder, general paresis, had clear clinical-pathological correlation. Indeed it would seem opportune that Alzheimer's disease can sit along general paresis as, noted by Ballenger (*ibid*) the second major form of

mental disorder to which a clinical pathology could be given. The reason why this didn't occur was based on Kraeplin's decision to see it as a pre-senile and rare form of dementia, and the difficulties at the time in considering dementia as a disease entity or as consequence of the ageing process. Amaducci *et al.,* (1986) argues that calling this new disease Alzheimer's disease was a way to identify this new clinicopathologic entity. Despite the differences in the representation of these histories, it is possible to conclude that Alzheimer's disease has historically been conceptualised as a pre-senile dementia, separated from senile dementia merely through age (Fox, 1989).

Alzheimer's disease however wasn't the only sub-type form of dementia being discovered as previously noted. Here again in the twentieth century, in 1922, Naville provided the best early description of the concept of subcortical dementia (Albert, 2005: 243), labelling it with the term 'bradyphrenia'. By 1932 the term 'subcorticale demenz' was then used by von Stockert (*ibid*). The term, and its associated clinical phenomena, came along at a useful moment in the history of science, encouraging scientists to refine their studies of dementia (Albert, 2005:244). This point is a useful one by Albert for not only does it allow some theoretical debate into the positioning of dementia as a concept but it also provides a discourse separate to that often dominated by Alzheimer's disease. However we are still left with a fundamental question – Why? The importance of how this reasoning came to be, the social apparatus and systems of thought that govern what can and cannot be said are of key importance here but would appear to remain unchecked. Vascular dementia, for example, was beginning to emerge also as a specific dementia phenotype in the late 1960s and early 1970s (McKay and Counts, 2017). Fisher, writing in 1968, argued that vascular dementia resulted from the cumulative effects of large and small strokes, soon followed by Hachinsky, *et al.,* in 1974 further supporting this view (McKay and Counts, 2017) and thus embedding vascular dementia firmly within the clinical domain. Additionally, in 1912 Fritz J.H. Lewy began to describe eosinophilic intraneuronal inclusion bodies (now more commonly referred to as Lewy bodies). This discovery led to further research by Woodward in 1962 in relation to mental decline and disease, culminating by the end of the century the first international

workshop on the disease in 1995 and use of the term ‘dementia with Lewy bodies’ (Mueller, *et al.,* 2017),

Earlier in the 1930s Ballenger (2006a; 2006b) argues that a different orientation towards dementia in psychiatry began to emerge that was based on social gerontology and psychodynamic models. Leading the developments in this area was Rothschild, an American psychiatrist, who chose to frame dementia as a psychosocial problem rather than a disease of the brain (Ballenger, 2017). His concept of dementia emphasized psychosocial factors over brain pathology. In this sense, dementia was a dialectical process between the brain and the psychosocial context of the ageing person. This became known as the psychodynamic approach, leading to a surge of interest again in age associated dementias. According to Ballenger (2006a) this supported a clear rationale for therapeutic interventions developed by psychiatrists and, more importantly, a move away from brain pathology to social-psychological theories. Sometimes called ‘social pathology’ psychiatrists such as Linden and Courtney argued that this in fact was the cause of brain pathology that led to senile dementia (Ballenger, 2006a:9). These ideas interested social gerontologists, an emerging field of study at the time focusing on adjustment to old age. However, the concept of ‘ageism’, as used by Butler in 1968, began to replace the psychodynamic concept of dementia (Ballenger, 2006a:10). Importantly this notion sought to question the growing link between ageing and dementia and the inevitability of senility and mental deterioration. This saw an attempt throughout 1960s and 70s to re-cast dementia as a disease, distinct from ageing. Roth, Tomlinson and Blessed (1966), writing in the late 1960s supported this connection between pathology and the clinical manifestations seen in dementia. They developed procedures for quantifying both the clinical manifestation of dementia and the number of plaques and tangles found in the brain (Ballenger, 2006a:10), notably disputing Rothschild’s claims. This was quickly followed by Katzman, a neurologist and later co-founder of the ‘Alzheimer’s Disease and Related Disorders Association (ADRDA)’, who argued that the distinction between AD and senile dementia should actually be dropped (Ballenger, 2017). Not only did he succeed in doing this, but he also successfully gave support for the view that

senile dementia was not part of the normal ageing process (Ballenger, 2006a). This view was supported by the research findings of Mayer-Gross in 1945, Roth in 1955, and Corsellis in 1962 (Hilton, 2015).

In addition, Ballenger (2000) argues for, what may be called, the middle period of the history of Alzheimer's disease, the period between brain psychiatry and biological psychiatry. Here, increasing attention was paid to inadequacies of the biological model as an explanation. Thus this period saw the growth of 'psychosocial factors' and psychodynamic models, popular in the 1940s and 1950s. This growth can be compared to the fact that none of the early twentieth psychiatrists actually provided any detailed or clear-cut definitions of Alzheimer's disease (Keuck, 2018).

Twenty-first century

The beginning of the twenty-first century shows clear parallels with reasoning at the end of the nineteenth century where biological sciences are viewed again as the source of explanatory models and therapeutic interventions in psychiatry (Whitehouse, 2000). An example of this can be seen in the 2005 revised criteria on the diagnosis and management of dementia with Lewy bodies by McKeith et al., (2005) and further research on Parkinson's disease dementia (Jebelli, 2018). In particular this proposed a focus on new clinical features (Mueller, *et al.,* 2017; Jellinger, 2018). Social factors that may affect the course of the disease have been relatively neglected as dementia is viewed as a biological condition with clinical manifestations due to brain pathology (Whitehouse, 2000). Vinters (2015) for example, discusses cerebro-spinal fluid (CSF) and neuroimaging biomarkers for dementia as being especially relevant to contemporary society due to recent developments in immunotherapeutic approaches that attempt to remove Aβ from the brain. Connections with aging also continue to emerge during this century, not solely because advancing age is seen as the biggest single risk factor for dementia (Dening and Sandilyan, 2015), but also because of a rise in aging research. Woll (2016) for example writes about the phenomenon of aging and

questions whether aging is the new disease for this century, striking clear parallels with early century discussions. This is because twenty-first century aging according to Woll (2106) is now disease focused. Her view is technology supported care, a core feature of this century, might actually change our view of aging from being a natural process into a disease focused phenomenon. Although she argues we should avoid this notion, her work begins to broaden the debate. Connections with frailty in older age, including cognitive as well as physical decline, is just one step away, with the next discussion more directly posited as to the role of assistive-technology in dementia care. The risk here is of aging being viewed as a disease potentially synonymous with frailty and dementia – a reversing of ideas linking the current phenomena of dementia to its early historical beginnings once more.

Published papers however on the history of dementia in the twenty-first century however are still lacking. This is interesting because molecular genetics and biology are making an increased appearance, possibly affecting how dementia is depicted, potentially replacing neuropathology and even neurochemistry, with the study moving from the human brain to the human gene (Whitehouse, 2000). At least 20 genes have been argued as associated with Alzheimer's disease for example, three genes associated with early-onset dementia accounting for one in every 1,000 cases, another gene (APOE type E4) with late-onset Alzheimer's disease. In addition some forms of vascular dementia, frontotemporal dementia and Huntington's disease dementia are caused by genetic abnormalities, with the latter as an inherited form with half the family member's usually affected (Dening and Sandilyan, 2015). Despite this, the historical overview of dementia in the twenty-first century appears neglected. One of the clearest examples of this is the lack of debate on the recently published DSM-5 (APA, 2013), which made a number of changes in dementia classifications (Ganguli, *et al.,* 2011). Under this system dementia is classified as a 'neuro-cognitive disorder'. It also includes a specific reference to the Lewy bodies as a diagnostic label for neurocognitive decline (Mueller, *et al.,* 2017) and Parkinson's disease neurocognitive decline (Jebelli, 2018). This is in contrast to the current ICD 10 (WHO, 1992) classification system where it remains grouped as an 'organic mental disorder'. The impact of

the subtle change in terminology both within and between diagnostic classifications systems has not been widely discussed in relation to dementia, yet remains of importance significance in what it means in contemporary society to be a person with dementia.

3.4 Summary

A quick summary of the history of dementia, as noted in this chapter, is presented in appendix 2. This history of dementia suggests the need to differentiate between 'term' and 'concept', changes in historical meanings and alternative terms/ affiliation with other disorders, reference to original, often archived, documents, an over-reliance and focus on discourses about Alzheimer's disease, and the possibility of subverted discourse. However the history of dementia, despite the diversity of dementia forms and types, is shown to favour the evolving discovery and naming of Alzheimer's disease (despite some notable exemptions as found in Amaducci, *et al.,* 1986; Engelhardt and Förstl, 2005; Grinberg, 2015, Halpert, 1983; Kassel, 1965; Kotsovsky, 1929; Loeb, 1995; Mckay and Counts, 2017; Mueller, *et al.,* 2017; Román, 1999, 2003; Schwartz, 1992; Torack, 1983). This may be one of the biggest challenges when discussing the history of dementia. As already noted in the introductory chapter, there are more than 200 different sub-types of dementia. Why, of all these types, only one, Alzheimer's disease, has received such favourable historiography and abundance in historical studies in comparison to the other types? This suggests a whole new undiscovered dynamic. Interestingly the literature review also found the term dementia had previously been used for a whole array of conditions associated with chronic brain disease (Blumer, 1907; Guiraud, 1943; Engelhardt and Grinberg, 2015).

We can also argue that the literature review found concepts of dementia had moved from a social model before the nineteenth century, to a biological model in the early 1900s, a return to psychosocial aspects mid-twentieth century and then back to a biological focus at the end of the twentieth century (Whitehouse, 2000). How this affects twenty-first century conceptualisations is interesting, and

here we return to the dichotomy as proposed in the introduction to this study – person centred care on one hand and medicalization on the other. How power, knowledge, truth as contained within the social apparatus of the time, the systems of knowledge and thought that support dominance, juxtaposes, changes, turns and wields itself to allow discontinuities and ruptures to affect Western conceptualisations of dementia were however mostly found missing.

Although some writers have however chosen to look at the social construction of dementia (Ballenger, 2006a; 2006b; Harding and Palfrey, 1997; Lock, 2013; Whitehouse, 2000), they may be argued to lack an appropriately articulated theoretical or sociological framework to hang these discussions upon. Although these authors discuss in poignant historical detail the social context of the history of Alzheimer's disease, they could be critiqued for neglecting understanding the true discourse and interplay of power and knowledge and thus arguably neglect subverted or less dominant discourse. Thus there is little evidence of understanding the power, knowledge and truth that underpins contemporary definitions, which, as argued by Innes (2009) leaves definitions partial, flawed and incomplete. Although this has led to some writers critiquing the medicalisation of dementia (Bond, 1992; Estes and Binney, 1989; Gubrium, 1986; Lyman, 1989) and others discussing how dementia may be socially constructed (Ballenger, 2006a; Harding and Palfrey, 1997; Innes, 2009; Whitehouse, *et al.,* 2000), gaps in our understanding still to remain and thus need to be explored in further detail.

3.5 Conclusions

The current model of science as a pure pursuit of truth leaves no space for broader explanations and hence all manner of social variables remain understudied (Berrios, 2010:5). Here we ask ourselves, was the original 1906 distinction between pre-senile and senile dementia based on anecdotal clinical observations, and was competition among universities one of the underlying determinants of this? The personal opinion of Kraepelin also played a major role.

Given his widespread reputation and authority, he generated a dogma that endures to this day (Amaducci, *et al.,* 1986). In studying only the 'great men' and how their contributions lay the foundations for current work in Alzheimer's disease creates problems for understanding the history of dementia (Ballenger, 2006a). This suggests a possible way of understanding the history of dementia as an example of priority debates, focusing on the role of particular people in the discovery of the disease (Keuck, 2018). This has all led to a series of gaps in the history of dementia. First of these gaps is the oversimplification of the actual historical development of science. Secondly, using history to legitimise the present can keep us from asking critical questions about the aims and limits of contemporary research (Ballenger, 2006a:5). However it is possible to show how history can help us understand (and not just legitimise) the present, and here we see potential for discovering instead the history of the present – a key principle in Foucauldian thought.

What we have found in our search of the literature is a historical narrative that includes a rather overt focus on Alzheimer's disease, with little regard to the other dementias. Many accounts begin with Alzheimer's first description in 1906, followed quickly by Kraeplin's naming of the disease in 1910. However as we have seen, this approach oversimplifies the actual historical development of the science behind the history of dementia. Indeed if we use this same history to legitimate the present teaching and education of professionals, limitations will arise. As argued by Ballenger (2006a; 2006b), there is a need to urge a broader view that understands that context is just as important as the doctors and scientists involved in its discovery.

In this sense, current histories of dementia appear largely to present a 'total history' of dementia. In so doing, we note that our literature review has shown what accounts for the medicalisation of dementia based on a homogeneous network of causality and relations, often through a clearly defined set of temporal frames of reference is depicted. The history of dementia is then divided into precise periods of time in order to depict a clear transformation of thought - it is reductive and totalising. This lies in sharp contrast to the 'general' history

proposed by this study which rather would seek to search for differences, transformations, continuities and discontinuities in the history of dementia. The aim here in this study is to see then beyond any historical caricatures and scientific discoveries of dementia, moving the historical discourse from one of periodization instead to one of conceptualisation.

What we also find missing is any reference to a listing or database of documents that support the socio-history of dementia. A 'dementia *Archive*' spanning earliest recorded times to the present day that includes both dominant and subverted discourse is therefore needed. First then through our archaeology method, we can create and examine what can be said about dementia, its 'archives of discourse'. Secondly, through our genealogy method, an analysis of power and the important history of the present can be examined, putting our newly created *Archive* to work. It is thus through both our archaeology and genealogy methods that we have the potential to see different ways for understanding the phenomena of dementia.

Chapter 4: Methodology

4.1 Introduction

Sweeney (2005) argues that historical research involves three important 'stages': (i) Identifying a researchable phenomenon, (ii) generating a hypostudy/question and (iii) accessing and analysing the data. This point is particularly imperative, given the underlying principle that historiographical research does not align itself to a specific set of methodological tools (*ibid*). The same consideration is arguably applicable to historical sociology and thus becomes a suitable methodological framework for this study. It is also recognised that intertwined through this framework should be the study's own epistemological approach, drawing upon post-structuralist and Foucauldian principles and echoed in its archaeological and genealogical discussions. Through both these approaches, core epistemological assumptions and ideas take shape and are used to seek out potentially marginalised discourses, which in so doing attempt to argue against total historical accounts and bring into question previous conceptual attempts about dementia knowledge. Here then the epistemological assumption is created - the dyadic relationship of knowledge/power and how they directly imply one another rather than existing in tension.

Our three stage framework however begins by examining the literature in order to clearly identify researchable phenomena. As detailed in Chapter 1, the researchable phenomenon here is the conceptualisation of dementia in Western society. Chapter 3 examined the published literature in this area. This generated several potential research hypotheses and questions, particularly surrounding its increasing medicalisation and a presumed dominance of psychiatry in naming dementia as neuro-psychiatric condition.

Ideas generated from the literature search are then applied to the second stage of this three stage framework, involving the formulation of a more focused research hypostudy to generate specific research questions. Here the research question is:

'*How is dementia conceptualised in Western society*?'

This process can also assist in identifying a theoretical framework to guide the interpretation of any subsequent findings (Christi, 1975), which, in this study, meant post-structuralism and the principles of Foucauldian analysis. Post-structuralism, using Foucauldian principles via framework analysis and documentary analysis will be the method employed to answer this research question. Taking on such a theoretical framework to support historical research clearly also differentiates this study from the more usual topographical or Whiggish historical interpretations, including the total histories as were found in the review of the literature.

The third and final stage of this process is further sub-divided into three smaller stages. Specifically it focuses on the location, access, and analysis of research materials and sources through documentary analysis to create and analyse our general history of dementia.

4.2 Methods overview

The starting point, stage one for this study was the archive construction - a carefully constructed *Dementia Archive* consisting of a set of documents that track what could be, what was, and what can be said about dementia in Western society (this is presented in appendix 3). The second stage was to apply the principles of framework analysis to these documents, highlighting themes and codes. This was the thematic coding stage. Finally, the third and final stage was to apply an in-depth analysis to these themes that would seek to clarify its conceptualisation using a Foucauldian approach largely influenced by the following questions;

- What is considered to be valid knowledge about dementia at a certain place and at a certain time?
- How does this knowledge about dementia arise and how is it passed on?
- What functions does it have for constituting subjects with dementia?

- What ‘kind’ of person is it to be a person with dementia?

4.3 Archive construction

4.3.1 Documents and their use

Despite featuring centrally in the research of sociologists (Scott, 1990), the analysis of documents is less utilised than other data collection methods (Macdonald, 2008). This can also be seen in the scant reference to documentary research often presented in methodological literature, which has been regarded as sparse and patchy (Platt, 1981a). Despite this sparsity, it is argued to be of no lesser importance, and has its own extensive history as a method of research (Macdonald, 2008). Examples of documentary research by sociologists were discussed in Chapter 2 (e.g. Durkheim, 1879; Marx, 1976; Weber, 1930).

A document has been described as any original written record, public or private, official or unofficial, which is printed or unprinted (Austin, 1958). As argued by Langlois and Seinobos in their classical text of 1908:

> “Documents are the traces which have been left by the thoughts and actions of men of former times. There is no substitute for documents: no documents, no history” (1908:17)

In essence, they are things that can be read, which relate to some aspect of the social world (Macdonald, 2008). However, such a definition could also move beyond purely the printed word. In this sense, a painting or a sculpture could also be *read*; to ignore this would create potential to disregard unofficial, subverted or less dominant discourse. This is an important point as it challenges traditional perspectives regarding documents, such as those held by Webb and Webb (1975 [1932]) who argued that there were two classes of material available to the researcher in this field: ‘documents’ and ‘contemporary literature’. They then defined a document as:

> "An instrument in language which has, as its origin, and for its deliberate and express purpose, to become the basis of, or to assist, the activities of an individual, an organisation, or a community" (1975: 100)

In so doing these authors were able to distinguish documents from contemporary literature, the latter of which, included poems, biographies, and other documents which were contemporary with the people, events or time under investigation. Importantly they argued this type of literature may be at risk of inaccurately and biasedly recording what happened. Scott (1990) notes that this may actually give background to the more official documents and thus, an adequate approach to documents must adopt a more general definition of documents. Documents may thus also include 'cultural objects' (Slater, 1998); 'paintings' (Bryson, *et al.,* 1991); 'personal documents' (Allport, 1942; Gottschalk, *et al.,* 1945); 'diaries' (Coxon, 1988); 'fiction' (Plummer, 1995); 'autobiographies' (Burnett, 1984); 'photographs' (Musello, 1979; Hirsch, 1997; Hall, 1991); 'magazines' (Beetham, 1996; McCracken, 1993); 'images, signs and representations' (Emmison and Smith, 2000; Tuchman, *et al.,* 1978); 'advertisements' (Williamson, 1978; Goldman, 1992); 'television, radio and film' (Seiter, 1992; Merton and Lazarsfeld, 1943; Ang, 1985): 'official statistics' (Kitsuse and Cicourel, 1963); 'patient records' (Berg, 1996; Macintyre, 1978); 'census details' (Davies, 1980; Hakim, 1980). This list of examples is not exhaustive. Given the limitations this study however only published documents in the form of text will be the focus. Recognising the richness and diversity of documents whilst also acknowledging what this study is excluding is an important part of its transparency. This is illustrated in Table 1 below.

Table 1: Inclusion/ exclusion criteria as 'type' of document

Document Type	
Exclusion Criteria	**Inclusion Criteria**
Adverts	Academic Textbooks
Autobiographies and Biographies	Professional Textbooks

Fictional literature (i.e. *Still Alice* by Lisa Genova and *The Wilderness* by Samantha Harvey)	National Policy
Magazines and Newspapers	Professional Guidance Papers/Reports
Paintings	Published Journal Articles
Personal documents (i.e. letters/ diaries)	
Television, Radio, Film, Plays, Theatre and Cinema	
Patient case notes (unless published as secondary material as part of a journal article or medical text book)	
Images, signs and other pictorial or diagrammatic representation	

To further understand this rationale a closer look at documents and their use in research is needed. One of the most famous examples of documentary analysis is Valla's 1439 analysis of the 'Donation of Constantine' (Arnold, 2000). Valla 'proved' that this document, which was argued to record the gifts and rights bestowed on the Christian church, was a forgery. His conclusions were based on a careful consideration of the language of the document, particularly the style of Latin used, compared to the style of Latin typically used in fourth century documents. This gave new thoughts on how the past could be studied and how to develop criteria on what constitutes truth (*ibid*). Interestingly, from a post-structuralism perspective, what constitutes truth is an important and ambiguous point as we progress with this study. This will become an important issue when trying to create a Dementia *Archive* for this study.

Drawing on the work of Platt (1981a) and Scott (1990), five areas need to be considered when constructing the archive: Establishing authenticity, availability, sampling, validity, and inferences of selected documents.

Establishing Authenticity

Instances where documents are not authentic or not what it purports itself to be, are numerous. This may include literary works or ideas attributed to authors who did not write them. Platt (1981a) argues that a falsified document may still be of interest but only if it is 'known' to be in-authentic. Procedures for establishing authenticity are therefore needed, but arguably according to Platt (1981a):

> "[only]…when it's worth applying such procedures; in practice the normal criterion is only to look closely when there is felt to be some reason for suspicion in a particular case, or when inauthentic examples of the class are known to be common" (1981a:32)

The notion of authenticity is particularly important to this research when considering work that is reproduced or translated by others. Drawing from the *Archive*, a number of documents are in languages other than English and thus, only translated copies can be considered. This is an important principle as the unavailability of original documentation remains a concern. Platt (1981a) provides an example of this issue in his discussion of Freud's analysis of Leonardo da Vinci's sexual attitudes, which were based on an incorrect reproduction of a detail in just one of his drawings. Thus Platt (1981a) provides the following guidance to question or give rise to concerns over the authenticity of any document that has been 'reproduced':

- The document as it stands does not appear to make sense or contains obvious errors.
- Different versions of the same original document are current.
- The document contains internal inconsistencies of literary style, content, typeface or handwriting.
- The document is known to have been translated via someone with an intellectual or material interest that the version given should be passed as the correct one.
- The version available is derived from a secondary source suspected on other grounds of being unreliable.
- The style or content are in some way inconsistent with that of other instances of the same class.

- It fits too neatly into a standard formula or literary form.

Availability of Documents

Platt (1981a) recognises that the sociologist may be limited to what can be accessed. Some documents may have never existed, others may have been lost or destroyed, and some may not be accessible. In the current study, many documents that were not available locally through University libraries or on the internet could be accessed through the British Library in London. Access to the 'reading rooms' was obtained via research student membership, which proved crucial for accessing some of the original documents. However, even though using the wide resources of the British Library, some documents remained elusive. Even though some were recorded as being listed on the library records, on close enquiry, they were found to be lost.

Interestingly too, documents that have never existed also produce their own problems. If only one set of documents were to be produced, this leads to clear misleading as to what actually went on. Inferences may be made based solely on what then becomes just one half of the story.

Platt (1981a) argues that when there is simply not enough data (or documents) one may be tempted to over-interpret from what is available, regarding this limited data as being representative. Importantly too, surviving documents may not be typical of the original field of thought, but actually more significant – the documents very survival indicating that they were more popular or highly valued.

Sampling problems

Generally, in documentary research, there are large numbers of potentially relevant documents. This has been discussed in detail above so will not be repeated here.

Validity

It is important to know how reliable and valid the accounts contained within the documents are. Platt (1981a) argues this concern should focus more on how the document is used rather than what it says. He provides the example of a picture that looked at solely as a work of art or looked at for the light it throws on the history - costume or furniture, at the time it was painted.

Thus we need to consider what criteria we can apply to help make judgements about the documents validity, including how the document is being used. Various attempts have been made to consider this including the work of Craig (1964). He emphasised the importance of direct witnesses and the need to examine the degree of proximity of a report. In a similar line, Naroll (1962) also argued that a ranking order of secondary sources by the degree of proximity between the author and the subject is important.

Despite these concerns, Platt (1981a) notes that relatively few research textbooks provide explicit guidance on how this could be addressed. This then becomes a key problem faced by researchers using documentary analysis as their method. Sometimes, to maintain validity, additional sources may then also be required to support the document.

4.3.2 Sampling

Document collection and creation of the *'Dementia Archive'* would ideally have been based on a previously validated and established list, which could then have been accessed as a sampling frame. However no listings exist in the subject of dementia studies and thus this needed to be created. The creation of such a list, here referred to as the *Archive*, would then also become a key output and contribution to the subject by this study.

However it is important to note that this would be a laborious task. This is because the titles of documents can be misleading and may not always allude to my specific area of research interest (e.g. how dementia has been conceptualised

over time). In addition, terms and concepts used in the documents to discuss dementia change over time, as noted from out review of the literature. This presents additional challenges also in distinguishing between uses of the ‘term’ and that of ‘concept’, combined with the diverse use of synonyms historically adopted for what we now call dementia (e.g. senility, dotage, dements, amentia, morosis, organic brain syndrome, fatuitas, bradyphrenia).

These concerns had to be considered when accessing documents for sampling. In this study, a two-pronged approach to finding documents therefore was adopted. First, a structured database search using the following search string or variations of the terms was undertaken: (dement* OR Alzheimer* OR senil*) AND (histor* OR concept* OR defin* OR construct* OR origin*) AND (medical* OR bio-medical* OR biomedical* OR social* OR psycholog* OR psychiatry).

Secondly, alongside the conventional literature search, a method similar to ‘snowball’ sampling, traditionally adopted in interviewing (Platt, 1981a), was considered. This involved examining the reference lists and bibliographies of the documents identified resulting in the finding of key historical documents.

This approach was considered appropriate as Sturgis (2008) argues, snowball sampling is used when there is no adequate list to use as a sampling frame and relies upon contacting participants and asking them if they know anyone else who would fit the same group criteria. They in turn, would be asked for contacts themselves in the same way. This process continues until no further group members or ‘sample representatives’ can be identified or obtained. This approach is similar to this study’s sampling method. There is however no clear guidance on how this may relate to documents, but the same basic principle of generating additional sources from one source, and then continuing until all sources had been potentially exhausted, was decided upon until a pragmatically maximum number of 500 was reached.

In this study, given the large collection of printed articles on the ‘history of dementia’ found as part of our literature search (see appendix 1), a careful examination of the reference lists and bibliographies that they contained could

then be undertaken for identifying original documents. These could then be compiled, and where appropriate subjected again themselves to further reference source examination. This would then produce the backbone of the *Dementia Archive*. Not surprisingly, a number of references were found shared across several papers.

In addition, given the rather recent expansion of interest in dementia, contemporary documents also needed to be considered. A number of accounts in our literature review confined themselves to specific time spans (e.g. the Greco-Roman period to the 1960s (Berchtold and Cotman, 1998); seventeenth and eighteenth centuries (Berrios, 1987); and, 1885-1920 (Holstein, 1997)). In other more wide-ranging histories, even when brought up to the present day by their authors, currency would remain confined to the time of writing. The publication dates, as noted above, give some indication to a period of recent time that has been neglected in the history of dementia. There are however some interesting exceptions, such as Whitehouse *et al.,* (2000), Ballenger (2006b) and, more recently, Lock (2013). However, limitations of these texts were their failure to relate the present to the oldest conceptualisations of dementia and the overt focus on Alzheimer's disease with little detailed reference to the other many forms of dementia found in older works, as well as the obvious disadvantage of periodization.

Methodologically when compiling this sampling frame it was important to know when to stop adding documents. Platt (1981a) argues that this challenge is easier if the research focuses primarily on influential documents. From a post-structuralist perspective however, this is open to criticism. Rather, research should consider the whole range of documents that originally existed, and not just those proffered by the 'scientific discovery'. Here having a clearly identified research paradigm is clearly beneficial, and in this study, following post-structuralism and using Foucauldian principles, both dominant, and importantly, subverted discourse also need exploring. When to stop adding documents then became an important concern. In this study this was based upon;

> "When all potential types of source have been thoroughly sampled and several further instances of each type do not bring anything new to light" (Platt, 1981a:39).

It also included a nominal 500 documents. This was so the *Archive* didn't become so large it became unmanageable as from a practical point, sufficient time and resource to carefully review each document needed to be considered. Time management and access to sources wider than the University library where the study was carried out (including researcher's own copies, digitised e-copies, inter-library loans, SCOPUS and visits to the British Library in London,) were then also adopted.

Document selection and sampling can therefore be summarised as adopting the following criteria;

Criterion 1: Review the documents used in the meta-analysis of the history of dementia, to obtain, where possible, original source documents.

Criterion 2: Carry out search for documents that represent the conceptualisation of dementia based on an understanding of the social apparatus of the time, with specific attempt to detect discontinuities, ruptures and repressed knowledge. This would include looking for alternative ways of 'speaking about' dementia.

Criterion 3: Systematic review of all official documents published in the twenty-first century, to include documents published in-between and after the published literature accounts noted in the literature review.

Criterion 4: Select the original document. However if this is not possible the following to be considered:

a) If the original documents are not accessible, then consider using copies, but make every attempt to establish their authenticity.

b) Original documents not written in English need to be reputably translated.

Criterion 5: Sample size – For practical reasons a maximum of 500 documents would be selected. Where documents are found over and above this number they will be considered in terms of adding any new or different perspectives

(based on principles of document familiarisation). If the discourse appeared to match those of already documents they would be omitted as data saturation would have already been substantiated.

This process of data collection established the *Dementia Archive*, comprising 500 documents that span 4,000 years (2000 BCE – 2016 CE). Notably, given this date range, a methodological decision to use the abbreviation BCE (Before the Common Era) rather than BC (Before Christ), and CE (Common Era) rather than AD (*Anno Domini*) is adopted as this shows a growing academic trend to avoid potentially Christian dominant discourse. The *Dementia Archive* became an important finding of this study. It is discussed in more detail in chapter 5 and is shown in appendix 3.

4.4 Framework analysis principles

Once the *Archive* had been created the documents needed to then be analysed. One of the most common approaches to analysing document qualitative data is thematic analysis (Javadi and Zarea, 2016). This involves going through a sequence of analytical steps to identify themes and categories (Braun and Clarke, 2006). Whilst its procedures are similar to some theoretically focused approaches (e.g. Interpretative Phenomenological Analysis; Grounded Theory), it is not wedded to any strict philosophical and theoretical underpinning. In other words, it is theoretically and epistemologically flexible (*ibid*). However thematic analysis has also been criticised for not providing sufficient reliability, transparency, and continuity (Guest, *et. al.,* 2012; Braun and Clarke, 2006). The notion of transparency was fundamental so a different method needed to be found. Framework analysis was therefore considered as an alternative.

Framework Analysis was developed by Ritchie and Spencer in the 1980s (Ritchie and Spencer, 1994) to address diverse social and public policy issues (Gale, *et al*., 2013). More recently it has been applied to health and social research, and is seen as an extension to thematic analysis (Lacey and Luff, 2007). In several ways it addresses some of the challenges highlighted above, and crucially provides a

transparent and detailed audit trail to help support the validity of created themes. This is achieved by the development of a matrix, usually consisting of rows or tables of cases (an individual interviewee or more specifically here in this study, a document), columns and 'cells' of summarised data (Gale *et al*., 2013). This structure enables the systematic reduction of data in order to analyse and report it in terms of themes, cases and codes. In this structure the context of the original cases is not lost, and the components of the themes are more transparent and accessible. Using ideas taken and adapted from both Gale *et al*., (2013) and Ritchie and Spencer (1994) for this study a framework analysis approach was therefore adopted and summarised in Table 2 below.

Table 2: Seven stages of framework analysis and its application to this research

STAGES	DESCRIPTION OF STAGES	APPLICATION TO RESEARCH
STAGE 1:	Data collection and transcription	All documents were in English written text format (either in their original format or as a translation). Dementia *Archive* created, spanning 2000 BCE – 2016 CE, and containing 500 documents.
STAGE 2:	Data familiarisation	Document immersion. All documents (or their relevant sections) were initially read and notes were taken during this process. Pilot a representative sample of 12 documents from the *Archive* for detailed analysis and coding.
STAGE 3:	Coding	After data familiarisation and analysis of the pilot 12 documents, coupled with previous knowledge, clear thematic codes are developed. Documents were re-read and codes applied.

STAGE 4:	Charting	Thematic codes were grouped together into categories/themes and clearly defined to form concepts and a working analytical framework.
STAGE 5:	Applying the analytical framework	The analytical framework was then applied to all documents by indexing them in relation to the framework codes and concepts.
STAGE 6:	Charting data into the framework matrix	A matrix was produced allowing charting for each of the six found concepts so patterns between these concepts within documents could also be note.
STAGE 7:	Interpreting the data (in-depth analysis using a Foucauldian approach)	The matrix provided a visual tool which was used to help present and discuss the themes from a post-structuralist perspective and Foucauldian principles as well as individual interpretation of each conceptual chart which latterly became the main focus.

4.4.1 Familiarization

Once the documents had been collected and the *Archive* had been established the general nature of the material required consideration. This included document immersion and was used to gain an overall feel of the *Archive* and the documents it contained. However as 500 documents were included it was felt inappropriate to attempt to look at each in detail – this would come later in the methodological process. Instead a selection of documents were selected from the *Archive* for pilot-analysis.

To select documents for this pilot-analysis the *Archive* documents were classified and sorted into types based on carefully considered definitions as shown in Table 3 below.

Table 3: Definitions of documents by type

Document type	Definition
Academic	Usually a textbook of some type providing guidance and/or information in regard to dementia studies. Usually printed, contemporary examples may also include electronic books.
Journal articles	Scholarly or peer reviewed articles, published in reputable journals, largely written by authors with expertise in dementia or an aspect of dementia care/management. Usually printed although may also include electronic and online journals.
Medical textbooks	A manual of some description, often as a book that describes in detail, using medicalised or clinical terminology, one or more elements of

	diagnosis, prognosis, treatment and/or management of dementia.
Policy paper or procedure	A formal document used to influence and or determine dementia care and/or practice.
Professional guidance	A document that provides clear professional standards for performance in dementia care and management

In addition, pilot-analysis selection needed to also consider examples that were illustrative of a range of time-periods. The documents selected based on this selection criteria are shown in Table 4.

Table 4: Example of document (*Archive*) familiarisation

Archive reference code	**Document title**	**Document type**	**Time period**
11	De Medicina (trans.)	Medical text	100
15	A discourse of the preservation of the sight: of melancholike difeafes; of rheumes, and of old age	Medical text	1599
29	Essays on the changes of the human body at the different disease ages; the diseases to which it is predisposed in each period of life and the physiological principles of longevity	Medical text	1811

35	A treatise on insanity and other disorders affecting the mind	Medical text	1837
77	Abiotrophy	Journal article	1902
85	Amentia and dementia: a clinic-pathological study	Journal article	1905
141	Case of Alzheimer's disease: relationship to senile condition	Journal article	1936
248	Need for hospice approach to treatment of patients with advanced progressive dementia	Journal article	1986
312	Dementia reconsidered; the person comes first	Academic	1997
366	Palliative care for older people: better practices	Policy paper or procedure	2004
378	Twenty years of the Alzheimer's disease amyloid hypostudy: a genetic perspective	Journal article	2005
468	Diagnostic and statistical manual of mental disorders – fifth edition (DSM-5)	Professional guidance	2013

Different types of key documents were selected - medical textbooks, professional guidance books or papers, journal articles, and policy documents, as well as different periods in time. These were felt to represent the range and diversity of documents contained within the *Archive*. These selected documents were carefully reviewed with key themes noted. Table 5 shows an example of how this was done for *one* of the documents, *Archive* Ref. 312, from the above table.

Table 5: Example of one document's key themes

Archive Ref	Document (in full)	Type	Key themes/ideas
312	Kitwood (1997) Dementia Reconsidered, the person comes first	Book	Challenge to medical model. Person-centred. Compassionate care. Focus on the 'experience' of the person.
Additional Theoretical Comments/Questions			
Was this the first challenge to medical ideas? Was this the first mention of person centred care applied to dementia? What does the discourse itself in the document reveal? How exactly does the text refer to dementia? Who, and what are the type of people called in the text that work with people with dementia? What is the potential relationship between the reader of the text and the text itself? What image of dementia does the text reveal? Are any institutions or professions reinforced in the text? What 'kind' of person does the text suggest a person with dementia to be? Are there any possible groups or categories of people who may gain or lose from this discourse? Does this discourse connect with other discourse?			

Following this process a good understanding of the types of documents held in the *Archive* were noted as well as a greater understanding of the diversity and richness of ideas. Notably however questions or comments about the

themes/ideas could begin to emerge (bottom row of the above table), here based on our Foucauldian principles, and in so doing the process of not only data-abstraction, but also Foucauldian conceptualisation could start to emerge.

4.4.2 Identifying a thematic framework

Once the selected 12 documents had been carefully reviewed and key themes identified, a thematic framework to sort the data into potential concepts and themes was then created. The focus of this framework was however based not only on the found themes taken from the documents but also *reflective* knowledge, that is knowledge that was largely descriptive and drawn from my previous personal knowledge as a clinician, academic and researcher, as well as ideas noted from the original literature review and the research aims and outcomes. Implicit in this approach was to source patterns for potential analytical themes which could be effectively refined when held against document examples. This approach allowed for a thematic framework that remained both responsive and sensitive to the research aims and Foucauldian principles.

Here it is important to note the need to make individual interpretations or judgements about the documents by the researcher, and thus it is clear to see why reflective knowledge, including initial data immersion and familiarisation of core ideas, are important. Additionally the post-structuralist stance and Foucauldian principles characteristic of this specific research approach also inform how judgements are made and meanings sought and thus, need to be recognised.

Findings therefore may actually be subjective, particularly given the reflective underpinnings and researcher interpretations (author bias in documentary analysis). This could prove problematic because it is important to ensure that the study could be replicated by other researchers. Reflexivity in the research process is therefore crucial and is described later in this chapter, Table 6 shows an example page of one of the many themed (or coded) documents. Here an extract is taken from the Dementia *Archive* Ref 312 (Kitwood, T (1997), ‘The

experience of dementia (Chapter 5)', In Dementia reconsidered: the person comes first. Buckingham: Open University).

Table 6: Example of part of a coded document

Page/ location of text	**Document text**	**Coded Themes**
p.70	'…for the greater part of the period in which dementia has existed as a clinical category, the subjectivity of those who are affected has been totally disregarded'.	Medical model conflict.
p.70	'In Britain, it [the experience of dementia] was clearly put on the agenda by Alison Froggatt (1988), but her pioneering was not widely followed'.	Subverted discourses. Power.
p.71	'Some glimpses of the way in which the experience of dementia may differ from one person to another can be gained from studies of personality. Within psychiatry this topic has been considered only very rarely'.	Psychological effects. Limits of psychiatric models.
p.73	'Malcolm Goldsmith (1996) has also presented remarkable evidence that people with dementia can express themselves, and argues strongly that their voices be heard'.	Disability models. Advocacy. Empowerment.
p.77	'Several years ago, after I had spent a good deal of time with people who had dementia in settings that epitomized the old culture of care, with its malignant social psychology and pervasive neglect…'	Changes in attitude. Changes in culture.

		Social-psychology. Person-centred. Negative views.
p.80	‘The dark picture of dementia that we have explored probably represents a state of affairs where psychological needs are, at best, only poorly met’.	Negative views. Psychological needs.
p.81	‘It might be said that there is only one all-encompassing need – love’.	Person centred. Psychology.
p.85	‘It is impossible to say, as yet, how many people might have this kind of [positive] experience if there were a serious and sustained attempt to meet their psychological needs’.	Person centred. Psychological needs.

A number of different thematic codes notably appear in the far right column for each passage. This shows the interconnection between potential themes that exist within the transcript – and importantly provides some support that conceptualising dementia is not a time limited nor linear process, as the collected histories of dementia in our literature review chapter had suggested. Using this thematic framework analysis thus, allows the researcher to see any patterns in conceptualising dementia, including, from a post-structuralist and Foucauldian approach, discontinuities, ruptures, juxtapositions and emergence of new ideas/thought. This thematic framework was then applied to all the documents within the *Archive* where possible.

4.4.3 Charting and conceptualising

The next stage within this framework analysis approach was to chart the themes together and to produce conceptualisations. This involved taking the original text

from each of the documents and then re-arranging them in line with the thematic approach. Our approach identified six main constructs. These were:

- Dementia and ageing.
- Dementia and mental disorder.
- Dementia and bio-medical disease.
- Dementia and neuro-cognition.
- Dementia and disability.
- Dementia and terminal illness.

These six themes capture a broad understanding that give a general direction or subtle meaning to the nature of the discourse. Themes emerge purely as characterisations of the discourse but importantly are also realised as potential dementia conceptualisations. As conceptualisations they then become a way to see and to speak of dementia in Western society. Table 7 takes the transcript example from document *Archive* Ref 312 noted above in tables 4, 5 and 6 and highlights how this document became conceptualised in this way, showing how it became charted under a theme, and later the concept title of 'Dementia and disability'. This procedure supported the consistent and transparent method needed for both ordering and making comparisons between documents.

Table 7: Example of charting a document's conceptualisation

Dementia conceptualised as a disability							
Archive Ref.	Person Centred	Relationship centred	Long term condition	Dementia friendly	Disability /Social models	Holistic	Social-psychology
312	X				X	X	X

The emerging patterns of ideas and themes thus become enshrined as concepts in their own right formulated through the above thematic framework analysis. This was made possible through a more serious process of detection. Charts and notes pertaining to the documents were interpreted to formulate an overall picture so as to find structure rather than simply focusing on any multiplicity of

discourse or documents. Post-structuralist and Foucauldian approaches were then adopted to analyse this data.

4.5 In-depth analysis based on a Foucauldian approach

The introduction and use of post-structuralism as a theoretical framework, as well as the introduction to the work of Michel Foucault, were addressed in Chapter 2. However in supporting the theoretical underpinning for this study it is important to review and expand on some of the salient or key features. In addressing the research questions of this study, the objective becomes one in which to analyse a particular way of looking at the concept of dementia and how this has developed over time, or periodization. This requires consideration of a number of core principles (power, truth, knowledge), commonly associated with the work of Michel Foucault.

Foucault's work is a common and frequently-cited exposition across studies into the life sciences. His approaches are often used in various ways and by observing differing emphases in his *oeuvre.* Notably however, despite his clear influence particular across the social sciences, his work did shift quite starkly in focus across his life rendering it difficult to conceptualise a coherent corpus of work (Yates and Hiles, 2010). For the purpose of this study, we begin at the end of his life-time work, with Foucault looking back on his own work and from a point of reflection characterising this as a 'history of problematization' (Foucault, 1984). Indeed Foucault's own approach to the history of problematization can be seen to focus not on the history of events as found in traditional historical enquiries, but rather on the history of systems of thought, giving rise to his famous aphorism that discourses "systematically form the objects of which they speak" (Foucault, 1972 [1969]:49). Thus our analysis is to find and uncover the process by which 'dementia' became a possible object of systems of knowledge, including how this became conceptualised and then re-conceptualised - or in summary, what does it mean to be a 'type' or 'kind' of person with dementia.

4.5.1 Power, truth and knowledge

In this sense, much can be taken from the work of the post-structuralist Michel Foucault, and, in considering methods both of, and for, analysis, his writings in *The History of Sexuality, Vol 1* (1978 [1976]) become important. In writing on the 'Method' for this work (*ibid*: 92-102), Foucault discusses conceptions of power that need to be understood in the first instance as a 'multiplicity of force relations'. He moves on to discuss a number of propositions saying much as to what power is not, before clearly arguing that power is exercised from innumerable points, that they are the immediate effects of a variety of inter-relationships, it comes from below, and power relations are intentional and non-subjective.

4.5.2 Foucauldian discourse analysis

To support a review of power, knowledge and truth contained within the *Dementia Archive* documents, principles of a Foucauldian approach applied to a framework analysis were applied to the data. An added important principle of this, as noted by Parker (1992), is that when attempting discourse analysis of this type, documents need to be read with the following preconditions/questions in mind;

> "Why was this said and not that?"
> "Why these words?"
> "Where do the connotations of the words fit with different ways of talking about the world?"
> (Parker 1992:4)

This generates, according to Parker (1992), an important reflexivity to discourse that if grounded in the post-structuralist tradition can be used historically in quite a useful way. In particular, following the work of Foucault (1967 [1961]) who described how a discourse about madness as a medical category came into being alongside an emerging medical discourse concerning human pathology that also became to categorise a particular section of the population, the same too we may see in our study on dementia. It is this possibility, which through a series of discourses embedded within the *Archive* that we come to understand

that the discourses about dementia used today are historically contingent. This understanding requires an unsettling of taken-for-granted forms of knowledge about dementia and in so doing, challenging what it is to be a person with dementia. It terms of dementia education and care, it challenges and unsettles dominant ideas in society.

A Foucauldian approach as part of our analysis allows us to critically review and question different ways of talking about dementia. For this to take place the data analysis must look for tensions inherent within and between discourses and consider various ways they both reproduce and change how dementia is conceptualised. Based on the work of Jäger and Maier (2009) our analysis can then be adapted to ask the following crucial questions;

- What is considered to be valid knowledge about dementia at a certain place and a certain time?
- How does this knowledge about dementia arise and how is it passed on?
- What functions does it have for constituting subjects with dementia?

Based on our established Foucauldian principles this analysis argues we are not just finding discourses about dementia, but rather pieces of discourse within the document. Such pieces are to be found within texts which then give a specific meaning to what was being reproduced. Here the study was able to explore the connotations, allusions and implications which the texts within the document evoke (Barthes, 1981 [1967]). This suggests that the document carries in its text different discourses that become available to different audiences. This is important when considering the medical, social, religious, naturalistic, scientific or psychological discourse on dementia.

Identifying the reality of what the discourse refers to and identifying the “practices that systematically form the objects of which they speak” (Foucault, 1972[1969]:49) should become an important goal for the researcher and was considered in this study. Understanding the discourse then as an object in its own right within the document, allowed further consideration of the relationship between the text (and not just the originating author) (the addressor) and those

expected to read it (the addressee). Post-structuralist questions as to what role has to be played by the reader to hear the message from the text, and how does this affect interpretation of the object of the discourse allows consideration of the relation or position to power the reader is placed in when engaging with the text. This includes positions that may be taken by the reader to resist it and thus sits well with our study's inherent Foucauldian principles.

Next we then consider how statements in a discourse can be grouped, and given certain coherence. Cultural understanding needs to be employed in acknowledging competing cultures may give different slants on the discourse, ranging from those whom the discourse benefits and to those whom it oppresses. The objective is to clearly recognise the discourse contained within the mass of text, and followed any of the discourse's recurrently used terms when characterizing or speaking about dementia. Based on Potter and Wetherell (1987), this study had to also consider if there was a limited range of terms used, or any particular stylistic and grammatical constructions when speaking of and about dementia. Much of this was drawn from our initial literature review as well as our charting of the differing types and forms of dementia.

Next based on cultural and possible political understanding of the discourse, consideration for any objectionable or subjugated perspectives needed to be considered. This may include social versus medical positions of dementia and associated ways of thinking or reconceptualising this disorder. This supported the charting, mapping and interpretation of the data within our framework analysis. The potential medical discourse, religious discourse, social discourse, etc. also needed to be examined in how they both relate and contradict each other and thus the interrelationship between different patterns of discourses.

Once the charting, mapping and interpretation was completed, then consideration of how the discourse reflects on its chosen terms for dementia needed to be ascertained. This would be important in encapsulating the conceptualisations from which they emerge. Examining for contradictions in the discourse and how other text would refer to these terms remained an important consideration of this. Here we give consideration to the assumption made by Billig *et al.,*(1988) that

any assertions in a discourse would also pose an opposing position, referred to as its 'implicit' rather than explicit meaning; Implicit meanings are, importantly, rarely voiced but are part of that way of talking about things. This involves making a judgement about the discourse as anti-psychiatry for example. Thus we end with discourse, implicit within the *Archive* documents, and one that continues to frame the way in which dementia becomes conceptualised, and frames the way in which people so labelled become positioned as subjects. Multiple conceptualisations of dementia may be for example merely multiple truths about the condition, each held in place by its own emerging discourse. Thus, as argued by Parker (1992):

> "Discourse analysis draws attention to language, and can help us reflect on what we do when we speak… both reflexivity and discourse analysis are historically and culturally bound….it reframes the object,… and allows us to treat it not as truth, but as one 'truth' held in place by language and power" (Parker, 1992:21-22).

4.6 Ethical considerations

Ethical approval for the study was requested from the De Montfort University Health and Life Sciences Research Ethical Committee. However following a discussion with the Head of Research at the time it was confirmed that as the study did not involve data collection from participants, then ethical approval was not needed.

This does not mean however that there were no further ethical considerations. It is in fact important to consider the epistemological position that I adopt as the researcher and author of this work. This is particularly important as I will use some degree of subjective experience, either consciously or sub-consciously, not only in what and how I select and interpret the *Archive* documents, but then in also how I choose to make claims about any of the research findings. There is thus an ethical need to consider and reflect on 'how I think' about what I am doing in this study. This means that I need to consider not only my professional training as a learning disability nurse and my practice as an Admiral Nurse (dementia nurse specialist) and how this training and my professional experience has shaped my

own ‘ways of seeing dementia’, but also to the intellectual assumptions that I hold as an author of this work that have potential to constrain, limit, permit, challenge or explore method, findings and/or any conclusions that I then ‘choose’ to make (this is discussed in more detail in the next section below on reflexivity in the research process).

A final ethical consideration was the concern that the findings of the research might cause criticism of the care of people with dementia, particularly if and where a medical or neuro-psychiatric model was still in use. The findings of the study however would be to show how the phenomena of dementia has changed in how it has come to be conceptualised; this then is not to impart judgement on what is or what is not correct, but merely to highlight difference and/or connectedness in how Western society uses explanatory concepts to locate and explain dementia or how they seek to problematize it. This is important if we are to consider how knowledge/power and ‘truth’ have changed, even over the last few years. It is important then to be aware, although importantly not to restrict the effect of the study’s findings and recommendations to any potential political undercurrents.

4.7 Reflexivity in the research process

It is important to take part in a retrospective reflexive inquiry examining my own approach for *Archive* selection and the discursive positions undertaken in this study. An important element of this is to reflect on my identity as the author, an identity that through the post-structuralist/Foucauldian principles I have used, is one with its own socio-history, is regularly revised, and, according to Hacking (1996:234) includes a variety of existing cultural texts which are woven together to ‘make up’ identity, and thus may be seen as discursively formulated. Importantly this includes how my own thinking has been essentially underpinned by my own epistemological viewpoint, and my professional reflexivity as a registered learning disability nurse and social worker, to have an anti-psychiatry bias, and the implications of this, particularly in relation to *Archive* document selection.

An important consideration is that this study, as forming Part 2 of a professional doctorate, is part of a much wider institutional practice and falls within a specific type of social-apparatus of governance that must also include economic, political and social changes in higher education. As such, part of the reflexive process also includes examining the conditions on which my work would be judged, which would then also affect my identity as author. This would provide alternative ways in not only reconstructing any previously held views but also would exercise limits on what can be said. The process of undertaking a professional doctorate programme will itself produce a specific effect on knowledge production, an outcome of reconstructing my own identity to fit within the institutional prerequisites.

To clarify what this means, my initial thoughts on what to research were partly framed by my professional identity as a learning disability nurse and social worker. I wanted to explore why dementia is seen as a psychiatric condition, whether other discourses of seeing dementia existed, and why, and how, this neuro-psychiatric conceptualisation came to become the dominant form of practice. My personal and professional view point places high value on the social model of dementia care. Here, my personal perspective is one where I believe the social construction of dementia (Harding and Palfrey, 1997), principles of person centred care and enriched/dialectical models of care putting the person first (Kitwood, 1997), listening to the voice of the person with dementia (Allan, 2001; Wilkinson, 2002) and holistic approaches (Downs, 2000) all shape an alternative to psychiatric/medical models. A social model I personally feel particularly highlights the premise of dementia as a disability, not a psychiatric disorder and thus supports fundamental beliefs in hearing the voice of people with dementia and their carers, acknowledging their personal and unique perspectives, the effect, which is often disabling, of environmental design and function, a focus on ability instead of disability, and an understanding of discriminatory practices embedded within thinking, practices and policy.

My own reflexivity and self-monitoring increased my concern that in *Archive* document selection, I could potentially undermine the medical model based on these core social model beliefs. Starting therefore with an outward facing critique of this concept, and one which I was consciously aware of, it is likely I would have been influenced in how I then 'found' documents for the *Archive*, based on a desire to avoid this type of bias. Thus, when I focused on this outward concern when deciding upon the collection and analysis of data, perhaps I inadvertently created a potential for the 'over-inclusion' of medical texts and an 'under-inclusion' of social/disability model texts as a clear attempt to reduce my anti-psychiatry bias. My analysis was therefore framed by a deliberate attempt to produce an *Archive* that avoided an anti-psychiatric bias. Examples of documents that were excluded from the *Archive* based on these notions, either because they failed to meet the inclusion criteria, or because further instances of this type of document, once the maximum 500 documents had been located, I believed would not bring anything new to light, need to be acknowledged. Some examples of these documents that did not feature in the *Archive* as a result of this, for purposes of transparency are shown in appendix 4.

The most noticeable part of the list in appendix 4 is that although ideas for each conceptualisation can be found, a large number of documents relates to either a social/disability or a bio-medical focus. This is likely to be a result of my attempt to avoid an anti-psychiatry bias. Although, if these documents were added to the analysis they wouldn't throw any new light to our understanding as documents of this type already appear in the *Archive,* exclusion may be considered justified (Platt, 1981a). However this attempt can also, on reflection, be seen as a clear limitation of this study as, on reflection, it may leave any discussion on the social/disability area weaker in terms of argument when compared to other areas. It would also suggest that by practically limiting the *Archive* to 500 documents, it has been left incomplete.

Self-monitoring in this case needed to be undertaken and a key element of this was through a detailed look at my epistemological reflexivity. For each document found a decision was made to include or exclude from the *Archive* with questions

such as ‘Why am I choosing this document?’ Or ‘What would happen to the overall project if this document wasn’t included?’ To support the reflexive process, methods such as diary keeping where recording my personal thoughts on the documents (including concerns over bias or self-doubt), supervised reflexivity through regular supervision sessions and introspection, all became useful tools in acknowledging and responding to my own personal voice and self-monitoring. Thus from the starting point of *Archive* selection, this study involved making conscious decisions about document selection. Moving away from an anti-psychiatric bias, and the risk of over-indulging in social and disability models for framing dementia, this provided avenues for constructing and reconstructing what I felt where subject positions of what it meant to be a kind of person with dementia. The findings chapter avoids reference to the thinking, learning and reflexivity that was undertaken as part of this doctoral pursuit, although does point to a clear questioning of dominant epistemological discourse and signals the prospect of counter discourse. However in attempting to limit my personal preferences that arose as a natural consequence through my identity as author, I may have acted to undermine and subvert, or rather underplay the section on disability/dementia as a long-term condition.

Importantly too, a professional doctorate programme must follow a given way of producing what is seen to be as disciplinary knowledge where my epistemic and personal claims are reviewed and judged through a system of thought. This is part of a much wider institutional or social apparatus that also governs what is to be said and not said, leaving my presumptions, claims, ethics, values and truths as depicted in my study all open to be examined. My findings and the associated discussion, the knowledge claims I make as an outcome of this study, are therefore also located as a product not only of self but also as a product of the social apparatus guiding institutional practices in HEIs. Thus, my submission of this study also becomes a natural acceptance of the power/knowledge located within these practices.

4.8 Summary

This chapter has aimed to provide a methodological overview that is clearly transparent of the work undertaken in this study, including some potential limitations. Various themes have been discussed ranging from an initial overview of how things were done, followed by a theoretical discussion of why these methods were undertaken. Taken together, Table 8 provides a brief but clear overview and summary of this research process.

Table 8: Research process summary

Theoretical Underpinning or Intellectual Paradigm	*Post-structuralism, with particular reference to the work and principles of Michel Foucault*
Methodology	*Qualitative*
Methods	*Documentary research*
Data analysis	*Framework analysis*

Chapter 5: Findings

5.1 Introduction

Principles of a Foucauldian approach involve two potential domains of historical analysis – archaeology and genealogy. This requires an analysis of the conditions of possibility for particular systems of knowledge for what can and cannot be said about an object (its archaeology), and then making connections to how such systems of knowledge and discourse are dynamically linked to the operation of power (it's genealogy). Dementia and its association with ageing and the psychiatric medicalisation, the growth of person centred care and emerging psycho-social models are examples of Foucault's ideas on (disciplinary) power and knowledge and thus the conceptualisation of dementia. Ideas on disciplinary power have already been discussed as the means by which bodies become subject to analysis and observation (Foucault, 1977 [1975]). In our study, the way in which people with dementia are brought to the attention of professionals, are then assessed, monitored, examined, and managed, become examples of this disciplinary power in action. At the heart of these practices is how dementia has come to be conceptualised.

It is this conceptualisation that forms the essence of disciplinary power in Western society and is the main focus of this study. The conceptualisation of dementia in Western society thus becomes a genealogical study about the relations between power and knowledge that represent the discourse describing this disorder. The current conceptualisation of dementia is thought to be a neuro-psychiatric condition, organic in nature and enshrined within a continued biomedical and psychiatric discourse. This is not a unique finding (see Downs, *et al.,* 2006). This view is further supported by the leading role currently played by mental health nurses and an overseeing of treatment and management by old age psychiatry. However this form of discourse has been constructed over time through a social history full of twists, turns, politics, discontinuities and ruptures. Any analysis must then go further than solely biomedical and scientific discoveries, or priority

debates that evaluate particular roles played by those in the discovery of the disease (Keuck. 2018). A systematic unearthing of the socio-historical ideas, rather than just the key events surrounding dementia, should be used to understand emerging events that punctuate its social history. However observations obtained from the past may not be, as Berrios (1995a:3) writes, "…epistemologically continuous with the present". As also noted by Hilton (2015) use of the terms senile dementia and dementia may not be synonymous when reviewing history. Owing to imprecise or changing terminology there is a risk that other disorders may be therefore included when examining historical discourse. This means there is a clear need to differentiate between the history of words (dementia, senile dementia) and a then conceptual history (the representation of the disorder we now choose to call dementia) – a term versus concept analysis.

As noted in our literature review, it was during the nineteenth and early twentieth centuries that the current 'medico' notion we have of dementia became constructed. Accordingly, many histories focus their attention on this period, although a wider understanding of how we 'got there in the first place' is needed. This makes it important to also understand causes for re-conceptualisations and what this may then hold for the future. This is the aim of this chapter - to present and critically consider, using an archaeology a genealogy, a socio-history of dementia discourse and thought based on a unique collection of 500 documents spanning 4,000 years, arguably the first collection of dementia thought in Western society, referred to as *The Dementia Archive* and displayed in appendix 3. Following discussion of the conditions of possibility that allow the conceptualisation of dementia to take place power is considered through a series of differing conceptualisations by its genealogy. This is finally presented, in Foucauldian terms as a 'general history of dementia'.

Overall this findings chapter shows that in establishing dementia was once regarded a normal part of ageing, the advent of rationalist modes of investigating the condition subtly changed this belief. This led to its problematization as a bio-medical disease and a mental disorder/ neuro-psychiatric condition, inescapably embedding dementia in a growing sociological discourse. Included in such a

discussion is the possibility of conceptualisations that now may also include neurocognitive disorders, disability and/or as a chronic health problem and terminal illness. These become this chapter's main findings.

The presentation of these findings is achieved in two part parts. In the first, key elements of the *Archive* are discussed, outlining its broad make up and composition. Key findings that may suggest a particular narrative for the discovery of dementia are highlighted that move beyond semantic disputes of use of the term and concept, a common objection when discussing terms and concepts that have the potential to change their frame of reference through time. This allows discovery for more than one single idea of what dementia is, but rather in recognising its conceptual heterogeneity, a multiplicity of concepts that are held in place by power/knowledge become revealed. These ideas are examples of discontinuities and ruptures in systems of thought and form the different conceptualisations of dementia located through its socio-history. This presents six socio-historical problematizations that have come to conceptualise what it is to be a person with dementia in Western society. First, we find dementia conceptualised as a ***natural consequence of old age***. To 'normalise' dementia in this way poses the question whether or not dementia actually constitutes a valid category or kind of disorder. This is important because for dementia to count as a disorder then it needs to be separated from what is 'normal' or ordinary. Here understanding and accepting dementia as a natural consequence of old age can only be made if old age itself were to be an illness. Our second and third *Archive* finding builds on this point but encourages us to consider whether or not it also constitutes a valid scientific kind. Two examples of scientific kinds are given, with dementia conceptualised as either a ***mental disorder*** or as a ***bio-medical disease***. The scientific basis for dementia is found through a series of histopathological and anatomical correlations between brain pathology and the symptoms of dementia. This bio-medical model/lens for conceptualising dementia is encapsulated through a series of scientific discoveries that attempt to accurately pick out clinical manifestations that lead to its explicit recognition through a system of approved diagnostic classification tools as a either a mental disorder or a bio-medical disease independent of old age. Our fourth *Archive*

finding sees a shift from bio-medical to cognitive and neurological features of the condition, conceptualised as a ***neurocognitive disorder***. The effect of this is a growing departure from medicalisation and psychiatry. The fifth *Archive* finding shows a further de-stabilising in medical influence, and re-conceptualises dementia as a ***disability and chronic health condition***, following a clear influence form social and disability models. Our sixth and final *Archive* finding, still largely in its infancy is dementia as a ***terminal illness***, supporting a growing emergence in the prognosis of dementia, palliative care and advanced stage management, culminating in a new system of thought – how to die well with dementia, rather than to just live well with the condition.

These six conceptualisations, or 'discursive practices' are examples of ruptures and discontinuities in systems of thought and form an overarching archaeology and genealogy of dementia thought and knowledge in Western society. What becomes clear through our emerging concepts is that psychiatry and medicine have not always played a central role in dementia, and thus there remains a need to describe and explore the nomenclature and classification of dementia through its socio-history. The changing conceptualisation of dementia demonstrates how emerging disease problems can be framed by societal values, knowledge and power. This leads to the possible sociological understanding of how psychiatry and medicalisation both enable, and are enabled by, the construction of dementia as a mental disorder. Our changing concepts of dementia then appear to lie at a clear interface between power and knowledge, the heart of any Foucauldian analysis. This promotes an understanding of the discontinuities and ruptures in the systems of thought surrounding dementia rather than just progress, evolution and scientific discovery. As these different conceptualisations come into being and discursive practices are critically considered, the process by which they can be viewed as accepted practices of knowledge and the tendency for them to undergo transformations to appear and disappear at particular times become important. Critical questions thus need to be asked, *'What forms of power operated? What is considered to be valid knowledge about dementia at a certain place and a certain time? How does this knowledge about dementia arise and how is it passed on? What functions does it have for constituting subjects with*

dementia? What *consequences does it have for the overall shaping and development of conceptualising dementia?*' In departing from traditional historicising and 'total histories' (see literature review) that focus on individuals or scientific discoveries, this findings chapter seeks to identify and discuss transformations in ideas and practices that have enabled the exercise of power to constitute what it is to be a person with dementia and thus produce a 'general history' and one based on conceptualisation rather than periodization.

5.2 Findings Part I: The archaeology of dementia *(the ideas of dementia discourse)*

Foucault's initial methodological approach noted most clearly in his early works has been described as his 'archaeology' (see Chapter 1). This approach is poised in opposition to traditional teleological histories that focus on developments over time that, as argued by Foucault (1972 [1969]) review the evolution of thought. Archaeology on the other hand considers the discontinuities and ruptures in thought. In this study our central question asks how dementia has come to be problematized, how this has continued or been shaped and through what means this has took place. This requires a re-visiting of traditional or total histories of dementia, examining how its conceptualisation as a societal problem, and thus its problematization, may be subject to change and disappearance. This can be compared to Foucault's examination of the much wider category of mental disorder to which he sought to uncover the rules to which such appearances and disappearances are subject (*ibid*).

Our archaeology has mapped the discourse of dementia, the documents by which it has come to be defined, differentiated, specified and thus conceptualised. Importantly however this was not simply just the reconstitution of a generic list of dementia texts, a point clearly advocated by Foucault, who noted that it is not simply 'discourses as a place where previously established objects are laid one after another like words on a page' (Foucault, 1972 [1969]:42-43). The importance here lies instead to understand how dementia had become

organised, transformed, problematized, and put into demarcated fields of discourse that lead to its conceptualisation. This is to ask how dementia could become a type of problem and conceptualised in a certain way including the rules and practices that would define it. Documents revealed in our *Dementia Archive* are discourses of practices that inform what can be said about dementia, influencing what it is to then become a person with dementia. *Archive* findings also reorganise the past events in the history of dementia to understand present day conceptualisations. This acts to position once trusted truths about dementia into doubt.

The *Archive* then presents us with an understanding of the relationship between power and knowledge. This is to consider how power and knowledge interact and support the structures needed, the systems of thought, that allow changes in conceptualisation to take place. However the uniqueness of adopting a Foucauldian approach is to also understand this interaction by focusing on the discourse of tiny events where conceptualisation is taking form. The *Archive*, containing 500 documents (see appendix 3), picks out this range of discourse, noting documents that some of our key dementia historians noted in our review of the literature may have not noticed. This allows an added possibility of providing previously unthought-of series of connections to which the conceptualisation of dementia in Western society is now composed.

5.2.1 The *Archive*

500 documents make up the *Archive*. Appendix 3 is provided to show which documents were included. For practical reasons this is presented as a list of published works, compiled in chronological order. However it is important that despite its appearance it should be regarded much more than just a list (Foucault, 1972 [1969]: 42-34) where “discourses… are laid one after another” and instead should be viewed as examples of “…practices that systematically form the objects of which they speak” (*ibid*:49). They span an approximate 4,000 years covering early Egyptian, Greek and Roman periods, as well as seventeenth through to the

contemporary twenty-first century. Noted in our methods chapter, this is not an inclusive arrangement of documents, it is exclusive, limited to 500 documents for practical purposes. Once the 500 had been reached, any additional documents found in the course of the study were considered in case they added any new details or offered different ways to problematize dementia. It was found however that the 500 documents selected did lead to a point of problematization satiation – further documents (see appendix 4) did not add anything new to the findings. For the purpose of transparency however, appendix 4 provides examples of some of these documents which do not form part of our *Archive* for these reasons, and thus for mainly methodological reasons fall outside the scope of this study, but are still to be recognised. It provides a range of examples for how dementia became an object of different types of conceptualisation, necessitating the exposition of the possible rules that allowed this to take place.

First, we can see from the *Archive* examples of how dementia became initially conceptualised as a natural consequence of ageing. To talk of 'being old' was to also give reference to failing memory and other cognitive abilities. Thus we also see the term 'senile' emerge as a term not solely applied to older age but also it's situating with cognitive decline and frailty in advancing age. To be an older person thus also denoted a person who was senile and lacking some degree of mental faculty. Here the strength of this conceptualisation lies in that older people themselves became to be constituted as a problem. As such, the older person and the person with dementia became largely inseparable and thus the problematization of dementia required a response from those charged with the care of the older person. Examples include the family and the church taking responsibility, something far removed from the present day in Western society where instead the General Practitioner (GP) becomes the 'responsible *clinician'* and gateway for service provision. An important secondary point to make here however is that although we have the church in this early period taking responsibility there is no sense of religious, spiritual or cultural connections to the condition. This early conceptualisation can be referred to as one occurring in the Classical Age. In consideration of our Foucauldian archaeology, we must however avoid any historical teleology assumptions to our analysis. Instead

dementia is reviewed within its own specific system of thought that existed at the time. However it is important to note that conceptualising dementia as a natural consequence of ageing at this time is not conceptually something that we have moved away from in contemporary society. A continued discourse that references dementia synonymous with older person care still remains. For example discourse can be found that states 'dementia is not a natural consequence of ageing' yet we still find the majority of references to dementia care in our documents focusing on older people. Additionally it is in the psychiatry of old age medical textbooks that we see the greatest reference to dementia. Thus we see that both the current conception of dementia as well as that found in the Classical Age have a pattern of continuity. If both are taken to have resulted from specific systems of thought or knowledge, then these patterns or 'rules' are still in operation today. To understand dementia in present day 'as a natural consequence' of aging is seen as misguided, but to ignore its presence as a possible conceptualisation would be to deliberately ignore the rules and practices to which dementia actually is still defined and ordered. In this respect, when interpreting our findings, critical distancing from the present is thus seen just as important as critical distancing from the past. A key finding here is that the conceptualising of dementia as a natural consequence of ageing is then not actually a product of a periodization as a total history on dementia might suggest. Thus, in taking our first *Archive* example of dementia conceptualisation as a natural consequence of ageing, we note that 'dementia' became an object of the discourses (particularly ageing and senescence) that have served to constitute it. Here the ways in which the older person coupled with notions of and about cognition become constituted and problematized, produce the possibilities for how we have come to speak about dementia. This has led to the conceptualising of dementia as this specific kind of person older person. Following Foucault's early work as already discussed above, *The Archaeology of Knowledge* (Foucault, 1972 [1969]), we can argue that the subject (here, the person with dementia) becomes a participant within any articulated discourse. However this is interesting for it gives rise to a potential presumption of linguistic determinism, whereby the person with dementia exists only within this articulated discourse

and thus remains bound or ordered by this discourse. This would suggest the dis-empowering of the person with dementia, rendering them a product of systems of thought and of any articulated conceptualisation or problematization occurring at the time. The discourse on dementia thus has correlations with progressive ageing and reduced cognition, validated and maintained by a growing range of professionals (such as the gerontologists) existing within each social apparatus (of any given time) with a clear reference of responsibility to the older person. The same systems of thought that give rise to what it is to be '*a kind of person with dementia'* also constructs, in the same way, the professionals and organisations judged to be able to diagnose, care and manage them. This is the root of our archaeology, and our first critical analysis of the *Archive* – the conditions to which particular systems of knowledge about dementia actually became possible.

However, the *Dementia Archive* also presents with its surface knowledge. It is a surface of all that is actually said about dementia but only within the limits and constraints of this study (its 500 found documents). Hacking (2004) importantly notes this is not the same as what is meant, intended or thought, but only what is finally said and in our case produced as an *Archive* compiled through our methodological practices. This is the surface of the *Archive*. It realises that to talk about dementia and use of this same term is not likely to be the same type of discourse when compared between early century and twenty-first century. This is similar to the argument made by Hilton (2015:183) who argued, "There is significant overlap between 'senile dementia', as recognized in the past, and 'dementia', as used in medical and lay circles today, but they are not synonymous. There is no precise equivalent for senile dementia." This is in part the difference between use of the 'term' and 'concept' for dementia. This allows for the surface of the *Archive*, containing its range of systems of thought, to have a potential varied discourse. This is resolved by shifting our concern from attempts to interpret the discourse to instead the relationship between different examples of discourse. This is summarised by Foucault who argued:

> "What counts in the things said by men is not so much what they may have thought or the extent to which these things represent their thoughts, as that which systematizes them from the outset" (Foucault 1973 [1963]:xix).

The *Archive* however is also rich in historical detail. This considers whether there are actual systems of thought in operation, throughout time, that produce definite laws and regularities that govern how one may speak of and about dementia, much in the same way in which Foucault, in *The Order of Things* (Foucault, 1970 [1966]) finds examples of organisation (Hacking, 2004). An archaeology of dementia thus rests on a quest for the unarticulated structures that come to regulate its discourse. Importantly here we are concerned not with the corpus of knowledge of dementia, typified in many current total histories of dementia as depicted in the review of the literature, but rather the *systems of possibilities*, what this study refers to as its conceptualisations. This allows discovery for 'what is possible to say' about dementia. Denoting in this way what is accepted and what is not accepted as rationale discourse about dementia allows claim to knowledge and power. In our *Archive* what counts as reason within the corpus of dementia knowledge will however always be or remain temporal. This suggests that the laws and regularities for governing what can and what cannot be said about dementia cannot be fixed. To conceptualise dementia therefore needs to be based on something far deeper than just surface knowledge from the *Archive.* We can see how this applies when instead of saying 'Alzheimer noted that…' we instead say 'the figure we call Alzheimer noted that…' Hacking (2004) notes this way of speaking to be an example of how Foucault would use or refer to the historical personalities. Here, although we are using Alzheimer's name, crucially we do so only in an attempt to refer to a text or particular form of discourse and not his *oeuvre*.

What we also find in our *Archive* is not only this *connaisance* – the ideas and beliefs that have come to be accepted by most dementia historians and that may lay path to current conceptualisations, but also its *savoir* – the possibilities through which this actually takes place. Could this from a socio-historical perspective be viewed as a 'dementia historical *a priori"*? The prospect of an *a priori* was considered in our methods chapter serving to underpin how discourse

within a document was categorised, coded and indexed. The *Archive* shows no evidence of a fixed body of thought, but rather the *savoir* of a particular time and type of person able to speak about or determine what could be said about dementia. It is in a state of flux.

The *Archive* can be compared to the principles contained within Foucault's *Madness and Civilization* (Foucault, 1967 [1961]). In this work, he suggests that madness is classified and treated (and effectively 'put away') by systems of society's own creation, thus creating not madness itself but rather the terms of which we come to see and understand what is and what is not mental disorder (Hacking, 2004). This can be observed when we lay bare the terms and conditions by which the phenomena of dementia is realized and thus its conceptualisation. Foucault notes two clear events, namely the great exclusion of the mid-seventeenth century (involving the building of asylums and the locking up of those labelled as deviant) and a much later liberation of new ways of dealing with the 'insane' including a growing new body of psychiatric knowledge (Hacking, 2004) that emphasize this point. In the same way, the *Archive* also points to a series of events that have affected the conceptualisation of dementia. This has included how old age came to be perceived initially as a disease and then as senility itself as a phenomenon became to be re-organised, changed. In addition it considers how these ideas later led to the emergence of a new discipline of gerontology and a new host of professions. This led to the understanding and separation of the psychological and the biological symptoms leading to the emergence of organic psychiatry. This further led dementia to become re-problematized as a neurological disorder leading to new ways of being a kind of person with dementia. Then disability discourse began to emerge, albeit subverted until the right conditions of possibility were in place to support the growth of person centred and disability models. Finally, we find a growing focus and emergence to die well with dementia, not just live well with dementia as previously projected by disability model. This development followed social and political concerns for palliative and end of life care importantly coupled with the eventual staging of dementia to include later and end of life stage. The conditions of possibility were then set for this new conceptualisation. Our *Archive* clearly

shows dementia in this way cannot be conceptualised as one pure thing, akin to Foucault's conclusion about mental disorder.

Taking this comparison one stage further however, Hacking (2004) argues that Foucault himself later began to question his once argued conceptualisation of madness as a pure thing and thus asked of himself;

> 'When I think back now, I ask myself what else it was I was talking about, in Madness and Civilization or the Birth of the Clinic, but power" (Foucault, 1980:115).

Interpretation of the *Archive* thus also requires a careful consideration of power and knowledge. There is a need for example to consider the emergence of the bands of experts, such as the gerontologist, the old age psychiatrist, the Admiral Nurse, to name but a few, that form to create new and changing conceptualisations as examples of this. Although in Ma*dness and Civilisation* ideas of mental illness were revised, they were still, for Foucault, maintained within an underlying concept of disease (Hacking, 2004). Applied to our *Archive* however there is no one underlying concept of the disease. This is because the kinds of things we can see that were once said about dementia are not the same that are said in contemporary' Western society. Importantly dementia as a term may be seen as unambiguous, but as a concept it actually denotes a new kind of object then what was first described in our early history (Hilton, 2015). In this sense, any attempt at forming a total history as found in many of the published histories would necessarily find itself to be flawed and incomplete. It is only through a general history, this study argues, that there is the ability to understand the potential multiplicity of dementia.

As we journey through our *Archive* we find new things begin to be said about dementia, not so different from what we see in Foucault's *Birth of the Clinic* (1973 [1963]). Again we have an exclusion of power relations but what we do see is the emergence of many truths, mirrored in our *Archive*. This is in sharp contrast to findings from our literature review which predominantly sought to describe the scientific discoveries and 'experts'. Instead this study finds a pattern of discourse for how to speak of dementia and what may have made this possible.

The conditions for which the dementia discourse takes place lie within Foucault's use of the word *'savoir'* – meaning the deeper rules that exist in determining what can and what cannot be said about a thing, clarifying both the truths and the falsehoods (Hacking, 2004). These then are our archaeological findings, the material conditions under which the conceptualisation of dementia has taken place. It includes the conditions of possibility of thought for particular systems of knowledge relating to dementia in Western society.

However Foucault also came to understand that the facts of discourse and mechanisms of power were not the same thing (Foucault, 1981). The archaeology of dementia on its own therefore is inadequate for understanding the conceptualisation of dementia. This is not to say that the archaeology of dementia wasn't warranted. But rather that it is a useful starting place. To however take this analysis further and to fully understand the socio-historical conceptualisation of dementia we must then look to its genealogy.

5.3 Findings Part II: The genealogy of dementia *(The mechanisms of power)*

Dementia, we have already noted is a phenomenon that means different things to different people, and not just different things at different times. The archaeology of dementia alone however proved insufficient in explaining this, and the forms in which this conceptualisation may take place need to be then further understood and can be revealed through exploring its genealogy. This includes understanding the formation of ideas not only on dementia, but also old age/ ageing, psychiatry, and understanding the brain and its functions, disability, chronic illness and of terminal care.

An important finding is that people labelled with dementia become a particular 'kind of person with dementia' dependent on the dominant conceptualisation not only of the time/ periodization but also of the legitimised notion of how we speak of it within the social apparatus of the governing institution, the conditions of possibility and the systems of thought at work. Any given conceptualisation would necessarily underpin and enforce dementia education, research and care practice. To trace a genealogy that offers differing conceptualisations is therefore suggestive that there is no such thing as a one unified description of dementia, but rather a disease that has been shaped and re-organised, constrained within systems that permit what can and cannot be said about it at any given period of time or organisation and remains dependent on much more than the 'simplicity' of scientific discovery or the diagnosing clinician. In this sense, the conceptualisation of dementia is more of a sociological then clinico-medical process (See Davies, 2004).

Our genealogy takes reference from the *Archive* and carefully moves on from the conditions of possibility of thought/systems of knowledge about dementia, to also include an exposition of the operation of power, something somewhat overlooked when just presenting the conditions of possibility alone. If systems of knowledge cannot be ignored from mechanisms of power, and in effect are actually intrinsically linked, then the power relations need to be unpicked. The starting point for understanding the genealogy of dementia is to understand power.

Power, for Foucault, was not one-sided. Power was redefined by Foucault who connected it to knowledge. Importantly when developing the *Archive*, it would be wrong to presume that the concept of dementia emerged through 'censorship, exclusion, blockage and repression' (Foucault, 1980:59) of ideas about the subject. Hidden within our *Archive* of discourse, a range of power-knowledge relations exist and thus the dementia ideas of our *Archive* alone, observable largely through our archaeology findings, will be insufficient if they neglect any understanding of the operation of power.

This then becomes the focus of our second series of findings. It is not to negate our previous archaeology, but rather to build on it. The archaeology provided six differing conceptualisations of dementia. However the power relations underpinning each conceptualisation require further attention and need, from our socio-historical perspective, to consider also the context in which they appear – the systems of relations and social apparatus, their application and their effect. Using the term adopted by Foucault, we could call this their "*dispositif.*" This becomes the subject of this part of the Findings chapter and is explored through a discussion of each of the six found conceptualisations of dementia. For practical purposes, reference is made to the *Archive* throughout this chapter, although only a limited number of texts are directly referred to. *The Archive* contains 500 documents and thus, to make reference to them all, would make this discussion clumsy and over-lengthy. Instead, some key examples are taken from the *Archive* that are considered illustrative of the principles being discussed, whilst also 3acknowledging that there would be other *Archive* references that could also be used to make this point.

5.3.1 Dementia as a natural consequence of ageing

> *"Loss of memory is the first humiliating notice of a change in the Cerebral Functions by age… In senescence, old ideas begin to be less easily recalled, and with whatever force new ones may be impressed upon the sensorium, they are sooner effaced than those that were stored up in early years. But it is also true, that the memory in many instances of great age, is nearly obliterated, and consequently the other mental faculties suffer a*

proportionate failure… In the SECOND EPOCH [capitalisation as in the original] of old age, the Decrepita Ætas of the ancients, which we date from the beginning of the 81st year, the scene of mortal existence closes… The system returns to the imbecility of the first epoch of infancy. The body staggers in walking; tears are shed from trivial affections of mind; drivelling takes place from the nose and mouth; the demands for food are frequent; the tendency to sleep is great; intoxication occurs from small portions of strong liquors; the mind is timid, and occupied with trifling objects; and a garrulous detail of past circumstances, too often characterize the period of second childhood. The physiological changes of this last age, produce emaciation; and rigidity of the whole body, which terminate in a state of universal palsy, and loss of circulation"

(Jameson, 1811:124,129-131)

This depiction of dementia taken from the early nineteenth century is a typical example of the association widely held between old age and mental and physical debilitation. In particular this relates to the mental symptoms resonating in cognitive and memory decline. Here we do not see dementia as a separate or isolated disease but rather as a natural consequence of ageing, and in this sense a continuum, of the ageing process. Importantly then there is an image presented not of 'dementia' as a disease, but rather of 'old age' itself as a disease. The 'gaze' is therefore focused on the problematization of old age itself.

This creates a particular system of knowledge that purports the ageing body and mind as requiring investigation and thus being subject to the gaze of others. To be an older person is to then also be a typical 'kind' of person that will be subject to the eventual succumbing of both physical and mental deterioration largely as a natural consequence of the advancement of age. This notion is enshrined in the Latin phrase '*Senectus ipsa morbus est*' – the idea that old age was a sickness or disease, an important fundamental belief for many early writers featuring within our *Archive*. This belief led to a logical conceptualisation of dementia as a natural consequence of ageing, as the following quotation from the historian Torack (1978) also shows;

"The evolution of senile dementia has traditionally been considered to represent an aspect of senescence which, in turn, is the normal final phase of human performance that occurs as a prelude to death. Yet there has always been vast disagreement regarding the meaning of this statement" (Torack, 1978).

Where this idea stems from, and how far in today's twenty-first century it reaches, remains an important consideration, and, as Torack (*ibid*) notes, one that is also debated. Conceptualising dementia as a natural consequence of ageing can be traced back to some of our earliest recorded documents in the *Archive* but so too can alternative ideas. Here for example we see clear differences in Cicero's *De Senectute* as he argues for old age as a life stage to be 'celebrated' and be given due reverence:

> "VI. … If, then, he had lived to his hundredth year, would he not be repenting of his old age? No, for he would not be employing his time in running and in leaping, or in long-distance throwing of the spear, or in hand-to-hand sword-play, but he would be engaged in using reflection, reason and judgement. If these mental qualities were not characteristic of old men our fathers would not have called their highest deliberative body the "senate"…"
>
> "VII. But, it is alleged, the memory is impaired. Of course, if you do not exercise it… Themistocles had learned the names of all the citizens of Athens by heart; …The aged remember everything that interests them… Old men retain their mental faculties, provided their interest an application continue; and this is true, not only of men in exalted public station, but likewise of those in the quiet of private life…"
>
> (Cicero 44BC, trans. Falconer, 1964:29-31)

Here, systems of knowledge that purport the succumbing to mental decline come under direct conflict. Questions as to why two so very different types of discourse are apparent need to be asked. One suggestion may be the temporal differences in periodization that split these two accounts, a logical argument that leads to many historians of dementia to categorise the history of dementia as something linear. Developed through the steady advancement of scientific discovery, this argument is used for accounting for changes in thought. However our results show something different. Our *Archive* reveals that discourse surrounding how older people are viewed sea-saws back and forth – there is no linear discourse based on scientific discovery or advancement in technology. What we find in fact is old age being revered, then medicalized, to next being viewed as active and valued citizens, to finally being considered or through the lens of frailty and dependency. This is clear example of how Western society has come to change

its views of older people flittering back and forth between both positive and negative conceptualisations. What determines these changing views, and what keeps them in a state of flux is not however scientific discovery, but rather the systems of thought that challenge and seek to problematize old age. Our depiction of old age is thus dependent on how it comes to be problematized. In a society where older age is revered, there exists within it a system of thought that counts lived experience as synonymous to the accumulation of knowledge – often depicted as 'wisdom'. In this sense to be wise is an asset and as both a term and a concept it conjures up images of respect and reverence. This then is a far cry from ideas that the reverence of old age might suggest that this was due to a society less focused on the value of cognition. In fact as we can see the opposite is in fact true. So why then is this not the case in more recent examples of discourse on ageing where, as in contemporary society, the phrase 'knowledge is power' and where hyper-cognitive attributes appear to act within as governing systems? One may suggest that whereas at certain periods of time knowledge was seen as *wisdom*, knowledge as *power* is actually a different dynamic. Essentially it requires a different system of thought. Contemporary Western society's notion of knowledge retrieval is based not on the accumulation of the lived experience and the scholarly activity of the individual, but rather on degrees of knowledge accessibility. Today's hyper-cognitive society relies on technology to do this, an instant generation of knowledge, to fulfil its needs. Knowledge (and thus power) in this instance is just a couple of clicks away. The need for the 'wise men and women' of the past has been made redundant by technological advances such as the internet and World Wide Web. With this redundancy a new system of thought has needed to emerge, one that has served to re-categorise older people not in terms of their lived experiences and accumulation of knowledge, for this is now retrieved far easier and quicker, but in a different way. To re-problematize the older person a different type of older person needed to be recognised. The gaze on the older person in today's society is an example of this, viewed as possessing two main concerns, one positive and thus removing it from previous problematizations, the other not so positive and thus seeking to re-problematize it once more. First there is a clear economic benefit that becomes

crucial for the continued functioning of society, and thus requiring adaptation of the social apparatus guiding systems of thought to support this. This may take the form of 'baby sitters' for grandchildren allowing for an economically productive workforce or as active consumers, spending collected pension pots either on themselves as or as financial support for their children/ grandchildren. The second role is one less advantageous to an ageing society and centres around a continued discourse in co-morbidity with a particular reference to frailty. Fried *et al.,* (2001) have discussed frailty as a complex interplay of weight loss, low grip strength, physical activity and walking speed, and self-reported exhaustion, although it may also include cognitive impairment too (Buchman, *et al.,* 2007). Contemporary society's ever increasing concern with the notion of frailty in older people may be justified in terms of dependency on services and the allocation of resources to elderly care. Specific job roles within health and social care professions have been created to 'manage' this growing phenomena and specialist 'older people and frailty' units have been set up to turn our gaze to this ever increasing problematization.

Here we find a unique and important link hidden within our *Archive,* seldom if at all discussed in other histories on the subject – and that is to understand dementia as a natural consequence of ageing, the first conceptualisation we have of dementia, is to actually understand how old age itself became problematized. Thus this is not about understanding a mental or neurological disorder and its origins, as has often been the case in published histories, it is rather to understand how old age became problematized itself as a disease. And indeed this idea may not be just one to be relegated to our historical past. Could in fact the recent gaze on frailty in the older person be in fact a slow re-emergence of dementia once again conceptualised as a natural consequence of ageing?

The differences between these two conceptualisations of old age are important. On first glance, and based solely on our archaeology, this may appear an example of a rupture or discontinuity in thought. However this poses the risk of conflating two potential themes – facts contained within the discourse with mechanisms of power (Foucault, 1981). A genealogical analysis based on this

idea thus suggests something quite pertinent – a power relationship that makes these changes in thought possible. Initially one could argue that the mere thought of writing of for example *De Senectue* was suggestive of a need to challenge the knowledge and thought of the time in relation to ageing. How the systems of thought of the time, contained within any given social apparatus, permit new ways of thinking needs further examination in this context.

Returning then to our contemporary problematization of frailty, we see this is not unique to our present time. Lucretius (99-55 BC) (cited by McMenemey, 1963) for example noted;

> "…when the mighty force of years
> Their frame hath shaken, and their limbs collapse
> With blunted strength, the intellect grows dim.
> The tongue talk's nonsense and the mind gives way
> And all things fail, and altogether go"

In this discourse we see again another clear connection between older age and the possible symptoms of dementia but as with before no clear separation between the two themes. What we find is an early discourse about frailty.

This is however not the only discourse found within our *Archive* connecting dementia to natural ageing. Willis (1684:211), in discussing what we would now refer to as dementia but at the time of writing considered it under 'stupidity or foolishness' notes;

> "although it chiefly belongs to the rational soul, and signifies a defect of the intellect and judgement, yet it is not improperly reckoned among the diseases of the head or brain; for as much as this eclipse of the superior soul proceeds from the imagination and the memory being hurt, and the failing of these depends upon the faults of the animal spirits, and the brain itself' (p.209)…. 'Stupidity might be …caused by ageing' …. 'Become by degrees dull… by the mere declining of age'"

The relationship between ageing and dementia is also not lost in some key literary works, most notably in Shakespeare's (1623) character 'Jacques' in his play *As You Like IT*:

> "Last scene of all
>
> That ends this strange eventful history [of humankind]
>
> Is second childishness and mere oblivion
>
> Sans teeth, sans eyes, sans taste, sans everything"
>
> (Act 2, Scene 7)

If such discourse then permeated the literary as well as the medical world, the characterisation of ageing and mental decline would become more naturalised.

Rush (1793) included again another early description of dementia and links to ageing;

> "The memory is the first faculty of the mind which fails in the decline of life"
>
> (Cited by Runes, 1947:349).

Importantly too was Pinel's reference to 'démence senile' (para 116) in *Nosographie* (1818 [1798]). This was the first known reference to senile dementia. Here then our discourse moves to a clearer formalization of which may be the starting point of a depiction of a specific disease, although its specific relationship to ageing has not yet been severed. This continued problematization with natural ageing continues throughout the nineteenth century,

Combe (1834:137) noted:

> "In old age… the brain has lost so much of its activity by natural decay, and the vivacity of feeling and energy of thinking are thereby so much subdued, that exciting causes of any kind have no longer the same impressions that they would have done in earlier life".

And again in Esquirol's 1838 influential '*Mental maladies: a treatise on insanity'* there is a continuous theme of dementia resulting from a natural consequence of ageing remains:

> "A malady which is so often the termination of a great many others, which is, so to speak, the constitutional condition of old age (1838:424)."

Here he defined three types of dementia (acute, chronic and senile) and to the latter type he noted:

> "Results from the progress of age. Man, passing insensibly into the vale of years, loses his sensibility, along with the free exercise of his understanding, before reaching the extreme of decrepitude. This form of mental disease is gradually established. It commences with a weakening of the memory, especially with respect to recent impressions. Sensations are feeble. Attention is uncertain and without impulse; and the movements are slow or impracticable (*ibid*: 435)"

Importantly this continues the problematization that dementia, particularly in the elderly, is not a disease but a natural consequence of the ageing process. Morel (1860) argued that 'loss in brain weight – a constant feature in dementia – is also present in ageing'.

An important and often under-estimated consideration in the writings of this time was the widely held belief, or system of knowledge, of cell-degeneration theory – an important nosological trend that considered old age as a separate from other age groups based on clinico-pathology rather than chronological age. In particular the work of Schwann and Virehow (1858) developed the idea of tissue degeneration through age with the ageing body unable to efficiently replace dying cells. To understand how this belief continued to support the idea that ageing was a disease in itself is easy to imagine, furthering growing discourse in this area.

Here, Beard (1874) uniquely described the relationship between a person's age and their ability to work. In particular he noted when speaking of deterioration in old age,

> "As the moral and reasoning faculties are the highest, most complex and most delicate development of human nature, they are the first to show signs of cerebral disease; when they begin to decay in advanced life we are generally safe in predicting that, if neglected, other faculties will sooner or later be impaired" (1874:8)

Maudsley (1879) in *The Pathology of the Mind*, noted

> "It is in this form of insanity that we are most likely to find atheromatous cerebral arteries, which, if they are not directly the cause, are at any rate the mark of a real decay of brain… With the decay of brain goes a corresponding decay of mind, the symptoms of which are

> characteristic. They may be described as exaggeration of the natural decline of mental faculties which often accompanies the bodily decline of old age" (1879:472-473)

It is important to note that at this time, arteriosclerosis was seen as the primary disease mechanism and a key cause of the pathological changes in old age (Beach 1987). The linking therefore between degrees of arteriosclerosis and senile dementia, rather than being seen as part of a bio-medical discourse, was viewed as purely age related.

Charcot (1881) (translated by Tuke 1881) further noted;

> "We shall have to remark, among other things, that the changes of texture impressed on the organism by old age sometimes become so marked that the physiological and pathological states seem to merge into one another by insensible transitions and cannot be clearly distinguished" (1881:27).

In these Lectures on *Senile and Chronic Diseases* we see him clearly demonstrating a marked interest to the study of diseases in old age. This notion helped incite discussion on whether old age itself was a disease and create the conditions possibility for others, like Mercier (1895) to discuss how the slowing of body activity, and loss of sociability lead to being bedridden, something he termed 'senile degeneration'. This allowed, through simple vernacular adoption, a furtherance to not only the problematization of old age but also what is to be an older person. An older person in this sense was to also be a person with dementia.

This presents a clear system of thought in developing ideas on what dementia could be. Within this pattern of thought we also know that Gowers (1902) coined the term 'abiotrophy' to describe the changes, which he importantly described as a passive process, that cause a progressive failure of the viral energy of brain tissue. His use of discourse here suggests that rather than a disease process, his argument represents a tangible link to again a natural consequence of ageing. Other similar correlations can also be found in the work of Russell (1902) who noted the ever increasing hospitalization of older people, and Pickett (1903) who noted approximately two-thirds of people over the age of 60 admitted to asylums had a diagnosis of senile dementia. To have a body of knowledge that informs a

given lens in which dementia and old age are seen as inseparable is enough to then perpetuate further systems of knowledge and thought that maintain this conceptualisation.

The idea that ageing itself was however something to be problematized is most clearly noted in the work of the American physician Ignatz Nascher. Nascher (1914) coined the word 'geriatrics' calling for the development of a geriatric speciality focusing on 'older age-associated' changes. He notes;

> "we realize that for all practical purposes the loves of the aged are useless, that they are often a burden to themselves, their family and the community at large" (1979 [1914]:12).
>
> "When the mind becomes impaired he neglects his person in every direction until he becomes obnoxious to those around him" (*ibid*: 483).

This showed the understanding of the time based on studies of the effects of ageing on the human body. This is interesting for the scientific understanding of morbid anatomy and histopathology actually supports rather than rejects this finding. Butler (2008:121) describes that although one of the triumphs of the twentieth century has been the increase in numbers of people living into old age, it has been at a price of an increase in the number of people with dementia. He noted in particular that "unless we find ways to prevent or cure Alzheimer's and other severe dementing diseases, the world will shortly be confronted with… the epidemic of the 21st century".

This gives us, according to Lock (2013), an undeniable association between ageing and dementia, reinforced by the lack of any effective medical treatment. This notion then represents the dominant ideas of the time, persisting well into the 19th century (Lock, 2013, 1993). Dementia is thus seen as a normal part of ageing. With the prospect of hindsight however we can see that this conceptualisation was purely reserved for senile dementia (dementia in older age). There is indeed little association with the many other forms of dementia as noted in our introductory chapter. One exception to this is 'dementia paralyticia' also known as neurosyphilis dementia or tertiary syphilis, although our *Archive* shows still only a limited amount of discourse on its problematization other than its connection with sexual behaviour. To link dementia paralyticia to the more

general concept of dementia would then also need to consider sexualised behaviour within the same context as older people's care and management. This was avoided by creating an idea of senile dementia and dementia paralyticia as two distinct pathologies, sharing in common only the word 'dementia' that carried weight purely as a term and not importantly as a concept. Dementia paralyticia was thus not problematized in the same way as other dementias and thus fell adrift from this conceptualisation. Interestingly this supports the notion that to be a kind of person with dementia would only be to be a kind of person who is old, preventing other conditions of possibility that dementia could exist only in the space of older age.

Later through our *Archive*, despite the official naming of Alzheimer's disease in 1910 (Kraepelin, 1910) and a growing interest in localisation theory, senile dementia continued to be associated with advancing age. Interestingly, it was in this same year that the plaques that Alzheimer had noted increased in this form of dementia became re-termed 'senile plaques', surely adding then to the confusion. This simple change in terminology served to add further support for the association between dementia and normal ageing, with Gellerstedt (1933) noting;

> "84% of persons dying over the age of 65 had 'senile plaques' in their brains"

And in so doing he added to this knowledge that senile plaques were a normal part of ageing, as well as a hallmark of dementia. Thus by association they became one in the same thing. What becomes striking here however is that dementia, in being seen as a normal part of ageing, was only made possible as a concept because ageing itself had become pathologised. Any diseases in later life were to become normalised purely as natural consequences of the ageing process.

Nascher (1911), one of the early gerontologists, argued;

> "Senile changes… [Were] deviations in degree… usually permanent, progressive, and uncontrollable; rarely remissive or changeable".

This reasoning continued to expand ideas that ageing was to be considered a disease, with Kotsovsky (1929) arguing that the onset of senility could in fact be delayed by reinforcing all tissues and organs, particularly those of the nervous system, and that this would delay the ageing process.

A clear link between the natural consequences of ageing and the growing ideas now to be found in a possible bio-medicalisation of dementia can be found in the early description of 'senile plaques' by Blocq and Marienesco (1892), later formally described by Redlich (1898) and confirmed by Bonfiglio (1908) and Perusini (1909) from our *Archive.* Here we see writers describing lesions resulting from a 'degeneration' leading to glial proliferation. Whether this was viewed as a natural consequence of ageing or the start of a bio-medicalisation of a separate disease is less obvious. What becomes clear is how systems of thought about what is and what is not possible begin to change. The problematization of dementia thus is caught amidst a rupture or discontinuity of thought – was it a natural consequence of ageing or a bio-medical disease, or even more fundamental, was this proof that ageing itself could be seen as a disease?

However it wasn't until 1911 when the term 'senile plaque' was formally introduced by Simchowicz who, in moving this discussion away from normal ageing to its bio-medicalisation) noted that;

> The mere presence of senile plaques does not necessarily indicate senile dementia. The number, arrangement, and size of plaques should be taken into consideration. The most important is the number. Four or five plaques… in one optic fibre can be found in the normal senium. However, while the normal old person on ninety-four years of age presents six plaques in the frontal region the senile dementia of seventy-two years of age shows 52 in the same region… Not only the number but the arrangement of the plaques is of importance. In normal ageing and in psychoses are more or less scattered, while in senile dementia they tend to show grouping. In addition to this, the size of the plaques can be of differential diagnostic value. In senile subjects without psychoses, small size plaques are encountered, while in the senile dementia one observes a giant form among the smaller and medium sized ones. The giant form is never observed in any psychosis except senile dementia" (1911:365).

The idea then that the disease was, or at least could be associated with ageing was not a new one, but the realisation that it were just confined to older people was. This presents a discontinuity or rupture in thought. Adding to what then is a newly growing system of support are views found in another earlier discourse from our *Archive,* that of Sheppard (1873) who notes the recognition of dementia in people under the age of 60. This premise however would however come with its own challenges. This is because seeing dementia as a disease not confined to older age would negate the previously held belief that sought to problematize old age itself. This view however becomes hastily becomes subjugated as further references to this type of discourse, particularly during this period, is not found elsewhere in the *Archive*. Rather what we find is debate on what is meant by, and the often applied stereotypes associated with, senility. This creates a portrayal of dementia as a problem of old age that is rendering with the term 'senility'. This change in term, which although literally meaning 'old age', becomes a societal diagnostic tool to apply to the older person who displays behaviour to which society wish to problematize. Senility, older age or dementia become the three terms of reference appearing in our *Archive,* used interchangeable whilst still supporting that old age ought to be viewed as a disease. This is an outward effect of the social apparatus giving way to systems of knowledge aiding the problematization of dementia.

Our *Archive* goes on to find that what could constitute 'senile' (supporting the use of the term senile-dementia) wasn't always agreed. Roth (1994) believed this to be symptoms appearing after the age of 60 years, whilst for Katzman and Karasu (1975) it was 65 years. This difference of five years may seem insignificant, but the need to categorise senility in this way does serve to draw the gaze ever closer to an association with ageing. The *Archive* finding shows that the use of the term senility and its association with both old age and confusion becomes a deliberate attempt to maintain this system of thought. Fundamentally debates about the age of senility are actually a debates about when old age ought to begin. This could be argued as a deliberate attempt to maintain that this disease was still a problem of old age, despite the newly emerging bio-medical evidence. This was

accomplished by changing the definition old age. If dementia signs could be noted in people who were 60, then old age itself would start at this point.

What however changed the course of thinking from a natural consequence to a bio-medical conceptualisation? Here we find in our *Archive* a subjugated discourse actually written some 100 years earlier - Beard (1874) speaking of a clear concern in understanding when 'senility' actually started;

> "When a man has passed into drivelling idiocy or helpless imbecility …[a] school boy can make the diagnosis but to tell just where idiocy and imbecility began may defy the ablest physiologist or pathologist" (1874:34).

Understanding where this separation lay and when someone was judged by others (or him/herself) to be 'senile' gave fertile ground to bring about a medical gaze to pathologise the ageing body. Indeed it can be argued that without this medical gaze then the pathology of dementia could not have then next arisen. Medical scrutiny gave way to the systems in place for the understanding the pathology of what we now understand as dementia. This supports a clear problematization of dementia associated with the ageing process. What started out as a 'natural consequence of ageing' evolved into a distinguishable form of 'senility,' which then grew into a conceptual disease in its own right. Systems of thought that permitted the problematization of ageing now appear to respond to competing discourse by re-categorising a singular state of ageing as senility. The creation of this newer and re-formed problematization is made possible not through advances in scientific discovery as traditional historiography on the subject suggests, but rather from a powerful modification of the term *senile,* from previously meaning old age to instead its association with mental decline and confusion. Importantly this is also distinguishable from earlier found archival concepts and their associations with the natural consequence of ageing. The emphasis is now found to be on mental decline, with no further reference to age-related physical debility given. This is an important idea and can be seen as a clear '*will to know'* (using our Foucauldian terms) in associating dementia to older age, whilst also alluding to a separation from physical frailty.

A discontinuity in thought is therefore created. Old age is no longer problematized as a disease. Instead, it is the effect on mental faculties and mental decline/ confusion where we see our gaze re-directed. So important has been this discourse that this concept of senility exists still well into the twenty-first century. In contemporary Western society, to be labelled as senile is still to be synonymous with the labelling of dementia. This concept is then truly not one we can accord to periodization as traditional historiography may lead us to believe.

An important and growing aspect of this newly emerging discourse is the changing dynamic of how the body is viewed. Our gaze, instead of being on the ageing body as a whole and any related interconnectedness for the systems of the human body and its effects on the mind as the 'body' ages, is directed instead to one specific area – the brain. To associate dementia as a natural consequence of ageing requires a system of thought that is entirely dependent on its association with the body. Knowledge of the brain as a distinct area of focus allows instead for a change in understanding, creating new directions in thought.

To understand the brain however was not also without its difficulties. Far from a clear move to the pathological, the brain-mind connection still lacked understanding. It was this lack of understanding, a gap in knowledge, which failed to allow or permit a seamless move to the pathological determinants of dementia. Rather, without any detailed understanding of brain-pathology, and the connection understood as the loss of mental faculties, a resulting problematization of behaviour which at times resulted in challenging, unpredictable and anti-social behaviour, subsequently gathered pace. A resulting connection and therefore new directions for the gaze focusing upon the 'mental health' occurred. This created a new conceptualisation of dementia as a type of mental disorder. It is this, the re-problematization of dementia as a mental disorder that we see emerging alongside the growth of the psychiatric profession that becomes the subject of our next discussion.

5.3.2 Dementia as a mental disorder

"Dementia - This, it will be recollected, is that form of general insanity, in which the mental functions are enfeebled. It is a condition of mental imbecility, or of fatuity, differing, in its complete form, from original idiocy only in the circumstance, that, in the latter, there never has been intellect, and the mind appears to be a blank, while in the former, the broken remains of a previous intelligence are generally discoverable. The affection is characterized, not by a want of ideas; but, by an entire want of coherence between them. The passions, the conscience, the will, may not be quite obliterated; but their exhibitions are generally feeble, fragmentary, merely habitual. An imperfect memory of the past remains; but present objects and incidents make no impression; or are forgotten immediately. …Dementia sometimes occurs as an original affection. It then first shows itself, as a general rule, in the failure of memory. The patient can usually recollect remote events; but those which are passing at the time make little impression, and are forgotten very quickly. Words are also forgotten, or ludicrously misapplied; persons and things being frequently called by the wrong names. Sometimes the patient appears to live in the past, and speaks of having recently visited old friends long since deceased, or of mingling in events which had perhaps occurred in his youth. The power of reasoning is gradually quite lost. The ideas may have a sort of concatenation depending on old associations; but the mind is wholly incapable of a train of thought leading to any rational conclusion. The feelings, the conscience, and the will, undergo a similar decay. …The man is reduced to a state of a brute without its instincts".

Wood, 1849:663-664

Understanding that cognitive decline was not purely a natural consequence of the ageing process had to wait until dementia could be viewed as a separate disorder or in its own right. However, once this was done, the type of disorder this then became would prove crucial to contemporary conceptualisations. The case example noted above taken from the mid-nineteenth century shows a new type of conceptualisation – that of dementia as a mental disorder.

Our *Archive* notes that importantly, in the early 1800s, mental disorders (or 'diseases of the mind' as it was known then), were not believed to have any particular 'structural substrate' or clinico-pathology (Winslow, 1854). Thus it was not surprising that bio-medical conceptualisations were absent. The focus instead was on behavioural symptoms as signs of abnormality – becoming the new problematization of dementia. This created a newly emerging separation from the

‘natural consequence’ of ageing, as dementia. Instead of normalizing dementia within the ageing process, our *Archive* shows evidence to support it grew to become an abnormal process, a dis-order, and thus its problematization as a mental disorder grew. Why would this change of direction? Not everyone gets dementia and thus it cannot rightly be a natural consequence of ageing. Despite the continued dominance of this idea as a natural consequence of aging, it would soon become obvious that many people would still live well into old age and not develop dementia. This it was a dis-order. Of interest here is to note that although previously if you did not develop dementia in older age this would be seen as abnormal, we now see a change or clear reversal in thought and direction. However, as we have continued to discuss, knowledge, power and truth about dementia is not linear – and thus even today for some people we find that to speak of an older person who doesn’t have any signs of dementia (or senility) is to be considered strange.

Our *Archive* notes that Prichard (1837) began to group dementia with other ‘insanities’ - recognising a system of thought that saw the problematization of dementia as a mental disorder. Its overlap with ageing however was then not rejected, there was no discontinuity in thought, as indeed it was still discussed as a disorder generally occurring in people over the age of 60 (Marcé, 1863), but a rupture in thought was emerging. Pritchard was not alone in his views. Barrough (1583) also considered the relationship between dementia and mental disorder, and as one of the earliest recorded *Archive* findings on this thought, makes the link between memory and reason in saying:

> “The loss of memory occurs sometimes alone, and sometimes reason is also compromised by it. It is caused in the lethargy and other soporiferous diseases…”

This problematizes dementia as emerging from a collection of signs/symptoms in relation to mental understanding. Thus it is of no surprise to find in *Nosographie* (1818 [1798]), that Pinel furthered this discussion on dementia by use of the terms morosis and amentia, explaining it as a failure in the association of ideas leading to disordered activity, extravagant behaviour, superficial emotions, memory loss, difficulty in the perception of objects, obliteration of judgement, aimless activity,

automatic existence, and forgetting of words or signs to convey ideas. The gaze is then directed to the observable symptoms of dementia, with no attempt to relate to its potential clinico-pathology. Dementia was problematized purely as a mental disorder.

Reference to associations with age however were still noted. As our *Archive* shows, Kraepelin (1910), in the eighth edition of his textbook on psychiatry argued for two forms of dementia, distinguished by age - pre-senile dementia which Kraeplin named 'Alzheimer's disease,' and senile dementia. Why Kraepelin did this has been the cause of much academic debate (Berrios, 1990; Lock, 2013) and may be summarised as:

- Pressure on Kraepelin to find evidence for a new disease.
- Kraepelin genuinely believed taxonomical revision was required for this 'new' type of dementia (Lock, 2013).
- Rivalry with a neurological department in Prague headed by Arnold Pick (for whom we now have Pick's disease named after, a form of frontotemporal dementia).
- Rivalry with Sigmund Freud and the competition from the growing psychoanalytical approaches to understanding mental disorders.

Interestingly despite Kraeplin's recognition of the 'Alzheimer' type of pre-senile dementia, our *Archive* notes a lack of research and commentary. This is important as it calls to question the actual impact this had at the time in comparison with today. Although today we recognise Alzheimer's disease as a common form of dementia particularly in older people, with prevalence actually increasing with age, the early twentieth century cites it as a pre-senile form. Was this why then it gathered little interest then as compared to today? Again this alludes to an interest in problematizing that predominantly problematizes the older person, even when mental disorders re considered. Other thoughts on why there was a lack of interest consider the range of not only economical but also political activities at the time, far overriding medical discoveries, such as the outbreak of the First World War. Here, resources were withdrawn from laboratories to rather support the war effort so further research aimed at this 'newly discovered disease'

would be hampered. Here we see how global infrastructures impinge on how a given social apparatus is able to develop or extend knowledge. This is not to say this was weakened however – rather it would seem, it was put on hold.

We note from out literature review the work of Lock (2013) who also argued that with the naming of Alzheimer's disease as a disease in the early twentieth century, it effectively became removed from the category of insanity and became reclassified as a neurological condition. However our *Archive* suggests this was not the case. Understandings of dementia commonly used in care management and practice follow what is now regarded a traditional conceptualization in which its construction as a biomedical disease and organic mental disorder is highlighted and perpetuated. It is this conceptualisation that, from review of our *Archive*, has had the most profound effect on dementia than any other. Rather we need to consider what is understood by the term organic mental disorder. For some this term may indeed refer to neurological disorders, but the continued reference and use of the term 'mental' shows a hidden motivation to keep this disease still chiefly embedded within psychiatry rather than neurology.

This dualism between psychiatry on one hand and neurology on the other has in its past shared many overlaps. Our *Archive* notes for example that during the eighteenth century there was a particular concern amongst neurologists about the' relationship' between the mind and body. This was supported by the idea of 'localization theory' which suggests neuropathological brain changes have a direct relationship to specific behavioural changes, with our *Archive* attributing these ideas to the work of Thomas Sydenham, a seventeenth century physician, who argued that diseases were waiting to be discovered and thus existed as specific entities independent of any human intervention. Notably this presents a complete absence of thought as to the impact of psycho-social considerations. The gaze here allows the expression for a form of problematization that becomes aligned within a medicalised framework, a shift in gaze between mental disorders to instead bio-medicine. Although a shift in gaze, the overall oeuvre still remains medicalized. Our *Archive* shows that this type of conceptualisation was still seen to dominate throughout the twentieth century. This suggest shifts and debates

are not based on periodization but rather the challenges and opportunities within the social apparatus to transform, as well as to subjugate, systems of knowledge and to continually defend selected truths. The power here, wielded chiefly by psychiatry, should not be overlooked or taken for granted. And more importantly, nor is this power situated at just one point of periodization, challenging accepted historiographical findings.

Within the *Archive* we find that the WHO, an internationally recognised and agreed classification of disorders still to this present day describes dementia as:

> "…a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. Consciousness is not clouded. Impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. This syndrome occurs in Alzheimer's disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain" (WHO 1992:45).

The significance of the medical model, particularly its focus on traditional psychiatric symptoms of 'deterioration in emotional control, social behaviour or motivation' (WHO, 1992) or 'cognitive deficits are present in many if not all mental disorders' (APA, 2013) is important when understanding the role of psychiatry in care management. This creates powerfully endorsed acceptance of the medical model, with specific reference to mental symptoms.

The other 'classification' text adopted within Western society is the Diagnostic and Statistical Manual of Disorders, published by the American Psychiatric Association (APA). This however appears to have had a varying degree of impact within the field of psychiatry, and thus its impact on how this has affected thinking on dementia requires review. From our *Archive* we note that DSM-I (APA, 1952) and DSM-II (APA, 1968) both in particular seem to have had little impact on dementia, and psychiatry as a whole. However its notion of dementia, as an organic mental disorder based on clinical impressions did serve to maintain some of the prevailing mental disorder discourse. However it is of interest to also note that with the advent of DSM-III (APA, 1980) a major change in how psychiatric

diagnosis was to be classified emerged, with categorisation based on the agreed positions of clinicians. In practice, this equates to diagnosis based on the observation of symptoms, which, having been formulated and coded by clinicians themselves, continues to reinforce a medical model bias.

Currently, as with the WHO (1992) noted above, the most recent psychiatric classification of dementia as a mental disorder contained within our *Archive* can be found in the latest publication of the Diagnostic and Statistical Manual of Mental Disorders (APA, 2013). Here, the principal focus is on psychopathology. Importantly this continues the earlier discourse of dementia as a mental disorder, but as an 'organic' mental disorder. Additionally, rather than posing any clear distinction between the normal and the pathological, as our *Archive* finds occurring in previous APA publications, DSM-5 by contrast presents a continuum approach to disorders – a continuum of low to high level severity. The risk of this approach however is over diagnosis due to the express inclusion of milder symptoms as still representative of the disorder categorisation. For dementia, continuums of mild, moderate and severe levels of impairment not only make it easier to receive a diagnosis but also the risk of seeing it once again as a natural consequence of the ageing process. This is system of thought is reinforced by the displacement of the actual term dementia with cognitive impairment, creating categories of Mild, Moderate and Severe Cognitive Impairment, as types of 'neuro-cognitive disorder'. To be a person with dementia is thus to be a person with some degree of cognitive impairment. Our *Archive* presents DSM-5 (APA, 2013) as a system of thought that replaces previous ideas about mental disorder by placing them on a continuum. This leads to question when does normal ageing and 'age-related memory loss' or 'Mild Cognitive Impairment' become dementia? This requires an understanding of the structures and systems, the social apparatus that are set in place to allow and permit this system of thought or knowledge transformation to take place. Given the ever increasing numbers of older people with dementia in today's society this provides a steady socio-cultural shift to reduce pathologizing and to re-normalise dementia as an increasing part of Western society. In this sense this knowledge shift presents a new system of thought about what it is to be a person with dementia.

Support for this way of thinking may actually be found through the brain scan, although this poses a potential dilemma for traditional mental disorders which cannot so easily be explained. Importantly, dementia has proved to be one of the few 'mental disorders' that has found a biological explanation, possibly adding to its attraction for psychiatric practice as this serves to legitimise psychiatry as a branch of medicine with scientific proof of the existence of a disorder. This presents a power struggle, not so much of recognising what is dementia, but rather the claiming of a disease to support a truth or legitimisation for the existence of a profession. Without such evidence the profession itself is called into question as there is a need to explain 'mental disorders' through neuroscience. This may then provide for psychiatry that one day mental disorders could be placed firmly within the field of neuroscience, thus legitimizing the profession of psychiatry as a specialism within medicine. This is this why dementia it is so important for dementia to be classified as a mental disorder and this 'owned' by psychiatry. A clear example of Foucault's ideas on power and knowledge.

The gradual increase of biological markers available to diagnose dementia might however become its undoing as a typical mental disorder. Rather, the growth of neuroscience actually supports dementia as a bio-medical disorder. How far this conceptualisation differs/interlinks with mental disorder v bio-medical disorder is interesting, indeed whether or not there is a separation at all. This will be the subject for the next part of this chapter.

5.3.3 Dementia as a bio-medical disease

> *"Dementia is a disease consisting of paralysis of the spirit characterized by abolition of the reasoning faculty. It differs from fatuitas, morosis, stultitia and stoliditas in that there is in these a weakening of understanding and memory: and from delirium in that this is but a temporary impairment in the exercise of the said functions. Some modern writers confuse dementia with mania, which is a delusional state accompanied by disturbed behaviour (audace); these symptoms are not present in subject with dementia who exhibit foolish behaviour and cannot understand what they are told, cannot remember anything,*

have no judgement, are sluggish, and retarded… Physiology teaches that the vividness of our understanding depends on the intensity of the external stimuli… in pathological states these may be excessive, distorted or abolished; dementia results in the third case; abolition may follow: 1. Damage to the brain caused by excessive usage, congenital causes or old age, 2. Failure of the spirit, 3. Small volume of the brain, 4. Violent blows to the head causing brain damage, 5. Incurable diseases such as epilepsy, or exposure to venoms (Charles Bonnet reports of a girl who developed dementia after being bitten by a bat) or other substances such as opiates and mandragora. Dementia is difficult to cure as it is related to damage of brain fibres and nervous fluids; it becomes incurable in cases of congenital defect or old age…"

Here, found in our *Archive,* we note that In the French Encyclopaedia (Diderot and d'Alembert, 1765) the very first time the term dementia conceptualised within a clear medical format giving rise to the nature of it as a bio-medical disease. This system of thought serves to distinguish it from some of the more common and traditional views of mental disorder of the time, with conditions such as mania (which at the time also included other mental disorders including schizophrenia) and delirium. This is a remarkable piece of discourse for a second reason; we see the first attempt to provide a clear definition of the diagnostic term 'dementia' and in doing so, the term is aligned with a bio-medicine. This *Archive* finding presents a clear discontinuity with other ideas or associations of dementia as a natural consequence of age or as a mental disorder as previously discussed.

Our *Archive* notes that Wilks (1864) had also followed this line of argument, giving a clear depiction of brain atrophy (shrinkage) and its association with dementia. This connection is important because if brain atrophy could be linked to mental disorder (as dementia was seen to be at this time) and not solely the ageing process, then justification for the development and progress of psychiatry could begin to grow. Wilks' work is interesting for it shows linking rather than tension between mental disorder and bio-medical conceptualisations. As we progress through our *Archive* we continue to find examples like this - parallel systems of thought co-existing between conceptualisations rather than overt ruptures. This creates not only distinct but also overlapping concepts. These overlapping patterns provide the emergent systems of thought that in turn come to shape socio-political discourse (what can and what cannot be said about dementia),

reforming the social apparatus permitting new (or old) conceptualisations or ways of speaking about dementia to both emerge and re-emerge. Taken from our *Archive*, Wilks is one example of this.

Another finding from our *Archive* was again an early piece of discourse, Marcé (1863). In this work dementia symptoms associated with motor function are explained by lesions in the basal ganglia, cerebellum and white matter, whereas cognitive deficits are associated with gyral atrophy and degeneration on neurons and other vessels. This creates a separation or categorisation of dementia symptoms into motor function and cognition. This system of thought provides an important demarcation from mental disorder and thus is used to indicate once more the emergence of discontinuity or potential rupture.

The *Archive* thus also presents a clear range of discourse with an ever increasing focus on the brain. Based on the work of earlier studies for example by Gowers (1902) on 'Abiotrophy' and Bolton (1905) in his studies of over 200 patients with dementia, we see an increased focus on the wasting of the prefrontal region in people with cognitive decline. Here the latter author concluded that it was this area that was responsible for intellectual functioning and that dementia was caused by atrophy resulting from insufficient durability of the outer cell layers of the cortex – a term he referred to as abiotrophy. It is interesting however to wonder was this to link dementia to the natural consequence of ageing or to describe dementia as an independent disease process. The way this would be ordered would depend solely on the system of thought operating at the time, permitting whether or not ageing itself was still to be viewed as a disease. If indeed Gowers (1902) idea of abiotrophy was based on a massive failure of the 'viral energy of the tissue' then the association between natural consequences of ageing is supported.

This way of thinking does show a gaze directed towards exploring the macrophology and histology of the brain, providing an important juncture in systems of thought. Foucault's discussion, in *Birth of the Clinic*, discusses how for example anatomical pathology, developing throughout the nineteenth century, supported the development of medical science. This science however drove

along one basic principle – a bio-medical disease needed to be sufficiently different from a normal individual. The increased dissection of cadavers in the name of science helped to maintain this distinction. Thus this development proved important in changing 'natural consequences of ageing' if distinct pathology could then become isolated. It was this that developed the idea of localisation theory, noted in our *Archive* in the work of Canguilhem (1904), which helped support a distinction between the natural consequence of ageing and bio-medicalisation, two distinct concepts.

What becomes apparent is on one hand we have *Archive* discourse showing an association between bio-medicalisation and mental disorder, running alongside a separate strand of discourse linking bio-medicalisation to the ageing process, and then another suggesting bio-medicalisation is a distinct concept in its own right. These tensions however do all have one thing in common, the clear attempt or oeuvre to medicalise dementia, albeit through differing configurations.

A more closer examination of this system of thought shows Alzheimer, together with his colleague Bielschowsky, arguing that their role in psychiatry was to move this discipline forward with the aid of the microscope (Braak and Braak, 2000). Arguably, his intention was to make clear links between dementia and some degree of neuropathology – a clear attempt to pathologise the condition. As noted by Lock (2013), Alzheimer wanted the medical world to realise that mental illnesses had a clear pathophysiological component. This is an important point when considering that around this time a theory of 'degeneracy' existing for mental illnesses. This theory strongly associated that certain categories of people were subject to declining problems, often brought on through immorality (behaviours such as excessive masturbation, alcoholism, excessive/ inappropriate sexual conduct). Such ideas gave way to a certain moral consciousness that supported the legitimisation of the care and 'control' of people with mental illnesses, as well as other conditions deemed fitting under this category. A brief look from our *Archive* at the Mental Deficiency Act 1913 provides us with some of these categories that allowed for compulsory institution. Typically such 'patients' were managed in custodial asylums. In equating dementia within

degeneracy theory was to then support this view of the condition. We do not find evidence that Alzheimer himself held this view for in attempting to find pathology for mental illnesses (including dementia) we see the move from mental illness to bio-medicalisation, separation from degeneration ideas. Bio-medicalization was a necessary step in this direction and its impact started to gather pace. This took the form of the new specialism 'organic psychiatry', an area persisting still to today where mental illness is often distinguished between emotional, functional and organic categories, with dementia entrenched firmly today in the latter. The views of Alzheimer were possibly shaped by a further *Archive* finding - Hughes (1887), a leading organic neuropsychiatrist of the time who argued:

> "There is no such thing as insanity without disease… involving the brain… There is no expression… There is no expression of mental derangement without a substratum of cortex disease, either in the neuron, in the enveloping membranes of the brain, in the nourishing blood supply, in the behaviour of the vaso-motor system mechanism" (Hughes, 1887:173).

Alzheimer, probably in considering such concerns, sought to make detailed notes on his observations of his patients to offer the presumed link between behaviour and then later clinical manifestations evident during post-mortem examination. His biographers (Maurer and Maurer, 2003) describe in detail his work in 1901 whilst a senior physician in the Asylum for the Insane and Epileptic in Frankfurt, with his 51 year old patient Auguste Deter. It is this extraordinary 'case study' that culminated in the depiction, 9 years later in 1910 by Kraeplin of Alzheimer's disease. Alzheimer is noted to have visited Auguste almost every day, taking extensive notes on her behaviour. Although he left the asylum, he still continued to enquire about Auguste, until her eventual death in 1906. The course of her dementia was documented as beginning in February 1902 and lasting till her death in April 1906. When she died, Alzheimer asked for her brain to be sent to him so he could perform an autopsy. This was a landmark decision and one that would not have been done had the concern to make a connection between mental illness and brain pathology not been considered.

Understanding the discourse, Alzheimer was not looking to understand and decipher the clinico-pathology of dementia but rather a new disease, and if not a

new disease at the very least to make connections between mental health symptoms and brain pathology. Importantly he was not looking for dementia but for something quite different – to re-conceptualise mental disorder as a whole, to link mental health to distinct pathology and to separate it from the growing interest at the time of psychoanalysis.

This clinico-pathology found by Alzheimer was only possible due to the contribution of two winners of the Nobel Prize for medicine. This, the 'silver precipitation technique', developed first by Golgi in 1873 and then Cajal. This was seen as an important breakthrough particularly in the neurosciences and had an important impact on the knowledge for this subject. This technique was refined once again in 1902 by Bielschowsky, importantly a colleague of Alzheimer; so it is no wonder that this technique was used to examine sections of brain tissue from the late Auguste Deter four years later. This allowed Alzheimer to 'discover' the extent and massing of neurofibrillary tangles that are now seen as the hall markers of this disease. Using a second technique, methyl blue-eosin, Alzheimer also noted the accumulation of amyloid plaques between nerve cells. Interestingly, Alzheimer's original slides were found in 1998 and his findings were confirmed as accurate by today's standards. Localization theory, as this began to be known, was continuing to subtly grow, with our *Archive* finding of Weber (1905) noting;

> "It is a fact now scarcely contested, that all mental disorders depend on pathological processes in the brain… in this sense every mental disorder may be termed a brain disease"

In November 1906 Alzheimer discussed his findings at a meeting of the South West German Alienists, in which he concluded;

> "Taken in all, we clearly have a distinct disease process before us. Such processes have been discovered in great numbers in recent years. This observation suggests to us that we should not be content to locate any clinically unclear cases of illness in one of the familiar categories of disease known to us to save ourselves the effort of understanding them. There are undoubtedly far more mental illnesses than are listed in our textbooks. In many such cases, a later histologic examination will allow us to elucidate the case" (cited by Maurer and Maurer)

Alzheimer's presentation however received little attention. He had presented a discontinuity in thought (localisation theory) but one that looked likely to be ignored or subjugated. Why this concept was not taken further at the time might be attributable to the growth of psychoanalytical theory – an approach clearly distinguishable from organic localisation and bio-medicalisation. Later in our *Archive* we find however a re-visit in interest for localisation theory emerging, particularly with the advent of dementia-sub types (such as Fronto-temporal lobe degeneration). Importantly today, neuropathological examination is now considered as the gold standard of diagnostic examination (Grinberg and Heinsen, 2010), but one that would require the right systems of thought and social apparatus to support its development. For Alzheimer, this was not the case and his findings did not match the operating systems of knowledge at the time – socio-politically society was not yet ready for these thought. Importantly, Alzheimer's work which so dominates present day thinking about dementia remained, at his time of writing and discovery, a clearly subjugated discourse – a point not always noted in some historical accounts.

A growing understanding of arteriosclerotic dementia, also known today as vascular dementia, was also starting to emerge. This is important because it provides a trace to a discourse that deviates from the dominant focus on Alzheimer's disease. Vascular dementia is the second most common form of dementia diagnosed in Western society, most often associated with strokes. From the *Archive*, Roth *et al's.,* (1966) study however challenges these views, noting there were few arteriosclerotic signs in the brains of people diagnosed with dementia post-mortem but rather that they showed evidence of the plaques and tangles that Alzheimer's work had previously described. This was an interesting development that caused effect to relocate interest back to the idea of 'Alzheimer's disease' as a growing focus for dementia, diverting attention back away from vascular dementia. Roth *et al.,* (1966) were able to provide evidence that the number of plaques and tangles found in the post-mortem brain equated to the severity of behavioural changes. Thus we see, through the particular work of Roth and his colleagues a focus from Pharmacy industries to Alzheimer's disease rather than vascular dementias, creating a powerful interplay of

knowledge and power to revisit the original findings of Alzheimer. It is now, and only at this point, where economic and socio-political forces seem to be in a position to create the right conditions of thought required to support a social apparatus that permits Alzheimer's work to take centre stage.

One of the most influential discussions also appearing at this time in the *Archive* is Katzman (1976). His work questions the distinction between pre-senile dementia (which to this point was labelled as Alzheimer's disease) and senile dementia. This accepted way of thinking was vehemently disputed by Katzman who argued that it was the pathology of the disease that was of diagnostic importance and not distinctions based solely on age of onset. This brought into contention any previously held ideas that dementia could be viewed as a normal pattern or natural consequence of ageing, ultimately challenging ideas that Alzheimer's disease was just a pre-senile form of dementia. The conditions for possibility of thought needed to challenge the work of Alzheimer's were now made available. This created a new system of thought.

From a bio-medical perspective, clinico-pathology began to move from basic pathology to neurology, creating a new way to problematize dementia. The table below (Table 9) shows examples that are to be found in our *Archive* demonstrate this.

Table 9: Biomedical advances in dementia

Pathology/ neurology	**Authors**
Pyramidal neuron damage	Mills and Schively (1897)
Granulovacuolar degeneration	Simchowicz (1911)
Fronto and temporal lobe atrophy	Willis (1672); Mingazzini (1913)
Gyral atrophy	Marcé (1863)
Neuron degeneration	Marcé (1863)
Prefrontal atrophy	Bolton (1905)

Senile plaques (also known as miliary sclerosis, or amyloid plaques)	Blocq and Marinesco (1892); Redlich (1898); Alzheimer (1907); Fischer (1907); Bonfiglio (1908); Fischer (1908); Perusini (1908); Barret (1911); Simchowicz (1911); Divry (1927);
Congophilic angiopathy	Alzheimer (1898)
Glial fibre plaques surrounding corpora amylacea	Alzheimer (1904)
Glial fibre plaques and proliferated or thickened axis cylinders (also known as Drussy necrosis)	Fischer (1907); Fischer (1908)
Neurofibril alteration, neurofibrillary tangles	Alzheimer (1907); Schnitzler (1911)

A recent development noted from our *Archive* is the growth in dementia genetics and molecular biology. One of the more classical studies in the search for genes associated with AD in our *Archive* is Pollen (1996) and his work on 'Hannah's Heirs' (commonly referred to as 'Hannah's gene'). Discovery and development of DNA have in fact revolutionised the study of genetics from inheritance (following classical Mendelian theory of dominant, recessive or X/Y linked traits, see McKusick, 1966) to DNA structure (correlations between phenotypes, mutations, cell changes). This has included the discovery of a number of chromosomes associated with dementia (examples include Chromosome 1, 12, 14, 19. 21, ApoE). Where we have chromosomes we have genetics. Such discoveries present a change in thinking from the *Archive* finding by Walton (1977) who having studied twin discordance, concluded that AD was in fact not inherited. Our *Archive* however also shows Cook *et al.,* (1981) considered this theory. His case concerned identical twins that developed dementia, but importantly over a decade difference in age of disease onset. The researcher's argument was that it was the environment and not genetics that accounted for the changes.

AD is in fact linked to multiple genes rather than just one, suggesting different mutations exist. This important discovery forced a shift in gaze from the previous linear models of causality. Importantly, although genetic factors increase the risk of AD, they do not act alone, as a range of additional environmental factors also play their role. Thus, genes do not act alone.

How this bio-medical gaze persists is noteworthy. The *Archive* finds that by the end of the nineteenth century, a change from previous philosophical interpretations of mental disorder becomes apparent. This is brought about through a growth in neuropathology awareness – a newly emerging system of thought. Many psychiatrists at this time were encouraged to undergo training in neurology and neuropathology (Zilboorg and Henry, 1941). This focus on bio-medical systems of knowledge acting to transform both how we speak of dementia and also mental health gains further ground, and possibly power, through our *Archive* finding of 'dementia paralytica' (today known as neurosyphilis dementia). This type of dementia became to be the first 'mental disorder' associated with a clear clinico-pathologic basis. This saw rise to a new system of thought and knowledge – that of the 'organic dementias'. With this focus on clinicopathology, a renewed focus with the brain became important. Discontinuity or change in thinking about dementia as a 'generalised cognitive disorders' gave way to looking for 'focal cognitive disorders' –paralleling previous thinking found in our *Archive* on localisation theory. These ideas were developed from knowledge about the brain, how it worked, and the functions of the cerebral cortex. Examples of this from our *Archive* include Meynert (1884) and Flechsig (1900, 1920). In addition, knowledge about aphasia (Wernicke, 1874; Lichtheim, 1885), alexia (Dejerine, 1892), apraxia (Liepmann, 1905, 1920), and agnosia (Lissauer, 1890) also provided a way to talk about the signs and symptoms of dementia in a way that could not have been discussed before. To talk of dementia now became a very different way to talk about it than before.

Focal dementias now became an important focus in the re-conceptualisation of dementia and provided new ways to speak of and about it. The systems of knowledge had changed and different truths were emerging. From our *Archive,* a

form of dementia to emerge, based largely on the systems of thought that made it possible to be able to speak disease and disorder in this different way, was frontotemporal dementia. The *Archive* notes the work here of Pick (1892), in his description of a 71 year old man with progressive memory loss;

> "The patient possesses a considerable vocabulary and speaks a lot; however, although sentences are sometimes correct when dealing with simple matters, they generally are nonsensical, partly because of the incorrect arrangement of words, partly because the words themselves are unintelligible. This is due at times to transposition of consonants, e.g. he says 'colmotive' instead of 'locomotive'…. We are not dealing with a disorder which can be exclusively, or even primarily, attributed to the simple amnestic effects of the senile process, but rather, it more closely follows those which are the result of focal lesions…" (1892:36-37).

Thus, prevailing discourse on the clinicopathology of dementia arose mainly due to the new ways of being able to speak about the disease. The bio-medicalisation of dementia created opportunity for this to happen. However, an increased attention to pathology led also to neurological findings and with this an increasing need to question, and to re-problematize dementia based on how society was evolving.

It is not hard to imagine that Western society today may be seen as a hyper-cognitive society. Success and achievement, goals and ambitions, developments and progress – all dependent on increasing levels of cognition. As Western society becomes ever increasingly dependent on the cognitive abilities of its citizens, a new way to problematize people would begin to grow. This creates the possibilities of thought to move or adjust the gaze from the biomedical to the neuro-cognitive one, this then being the next conceptualisation found within our *Archive* and the focus of the next part of this chapter.

5.3.4 Dementia as a neuro-cognitive disorder

> "Thus we see a 54-year old man who slowly and imperceptibly and with no impairment of consciousness or seizures develops a state of profound mental impairment with prominent agnostic, aphasic, and apractic disturbances. A more accurate analysis of these focal symptoms present various problems because the impairment of recognition, language comprehension and expression, as well as praxis, the general impairment and reluctant behaviour, make the interpretation of individual verbal capabilities and acts difficult. It is, however, certain that the language disturbances of the patients have to be considered as transcortical aphasias because of the long-preserved ability for recognition. Since there was an early impoverishment of word production which progressed to a complete loss of spontaneous language, we have to assume a mixed motor and sensory aphasia in spite of gross signs of paralysis. Of the apractic disturbances, although these were sometimes purely motor, ideational apraxia was more prominent. In contrast to the severe disturbances of language and of praxis, disturbance of motility was slight and the absence of real signs of paralysis of the extremities was striking. In the late stages of the condition and towards the end of life, repeated epileptic attacks and a transient right-sided facial nerve paralysis occurred."
>
> Alzheimer, 1911 (translation, Förstl and Levy 1991)

Depicted in our *Archive* finding noted above from Alzheimer (1911), consideration for the neuro-cognitive conceptualisation of dementia is shown. This requires careful analysis in how far cognitive decline has become a central feature of dementia. This system of thought represents a marked change in the problematization of this disease then previously discussed in discourses that focused on the behavioural problems or symptoms of dementia. Our *Archive* for example shows Fernando, *et al.,* (2004), Jellinger (2007), and Schneider, *et al.,* (2007) all pointing to an ongoing discussion of the overlap between two common types of dementia, VaD and AD, but still, even with increasing developments in understanding the pathological distinctions as noted earlier in this chapter, cognitive decline (rather than pathology) remains the key criteria. Thus, despite the type or form of dementia, to speak of dementia in this sense is to speak of it in terms of cognitive deficits resulting in a change to its conceptualisation.

Dementia comes to be determined through psychological testing and through the measurement of cognitive decline. To demonstrate the neuro-cognitive conceptualisation found within our *Archive,* the '*Nuns study'* (Snowdon, 1997) is of particular classical importance. This longitudinal study started in 1986 and

remains running to the present day. It involves 678 catholic nuns belonging to the Order School Sisters of Notre Dame in the United States. Importantly, letters written by the nuns when applying to enter the Order were uniquely kept and later matched with neurocognitive tests administered when they reached the age of 75 and continued thereafter. The nuns had also agreed to donate their brains on their death for autopsy with the results – the initial letters, the neurocognitive tests and the post-mortem results, compared. The principal finding was that nuns who had shown early imagination and complex thoughts (what Snowdon called 'high idea density') were less likely to develop dementia. Conversely, nuns who had low idea density (particularly in their early 20s) had a much higher rate (90%) of neuropathology. Such findings have, and still to this day, give rise to the concepts of a 'cognitive reserve hypostudy'. Post mortem however, the results are quite interesting too and have served to question the bio-medical conceptualisation as discussed in the previous chapter. Some of the nuns who did well on cognitive tests showed post-mortem pathological changes associated with dementia, whilst again some of the nuns who did not do so well had no obvious pathological signs. In addition with this latter group, a number of the nuns also exhibited behavioural signs of dementia that were then not evidenced post-mortem. Snowden (1997) notes:

> "Sister Mary… was a remarkable woman who had high cognitive test scores before her death at 101 years of age. What is more remarkable is that she maintained this high status despite having abundant neurofibrillary tangles and senile plaques, the classic lesions of Alzheimer's disease" (1997:150).

A second recent study taken from our *Archive* by Sava, *et al.,* (2009) of 456 people who had agreed to donate their brains for research and had been given a diagnosis of dementia showed again some interesting and unexpected results. Noting that all these individuals had been given a formal diagnosis (of Alzheimer's disease) it would be expected that they all would show the classic pathology of plaques and tangles in the brain that the bio-medical conceptualisation would leave us to believe. However this pathology was seen only in the group aged 60-75, but after 75 years of age the pathology was importantly less consistent. Crystal, *et al.,* (2000) also found similar results noting that people over the age of

80 years with a previous diagnosis of dementia, rarely actually met the post-mortem diagnostic pathological criteria.

What all these studies from the *Archive* show is discontinuity from previous localisation theory and the bio-medical perceptions of dementia. Instead systems of thought centre on an increasingly neuro-cognitive discourse. To talk of dementia now then then is to talk about it in terms of degrees of cognitive deficit.

An important element of this neurocognitive conceptualisation may also be traced in *Archive* to the work of Roth (1994), who proposed the idea for more discussion on what he called the brain's 'reserve capacity'(sometimes also referred today as neuro-plasticity). Importantly this argument was generated at the same time as Lishman's re-conceptualisation discussion that Alzheimer's disease was a normal part of ageing. These two theories thus battled over normativity once again. Central however to Roth's (1994) argument was a 'neurocognitive' conceptualisation, although he did not use the term. His argument centred on the symptomology of dementia (and in particular Alzheimer's disease) that included identity loss, information retention and capacity for reasoning (in addition to memory loss). Such discourse produced an alternative lens to which one could gaze at dementia, here giving focus to the 'cognitive abilities' rather than to gaze upon post-mortem pathology. To say however this frame of reference was one of twentieth or twenty-first century ideas would be wrong. Our *Archive* indeed unpicks a key text taken from an early use of the term 'dementia,' found in Blanchard's Physical dictionary (1726) where it was referred to as an equivalent of 'extinction of the imagination or judgement' (p.21).

The diagnosis of dementia depends on where the gaze would turn. According to DSM-III-R (APA, 1987) for example, the diagnosis of dementia was made mainly on the basis of cognitive symptom loss, with more than just one cognitive function being impaired including memory problems. This may include abstract thinking, judgement, higher cortical functions, visuospatial skills, motor performance, emotional function and finally personality change. More recently, our *Archive* also notes that also in its most recent editions, DCM-5, the APA, (2013) has rather

specifically placed dementia within the broader category of 'neuro-cognitive disorders' (NCD):

> "…the primary clinical deficit is in cognitive function, and that are acquired rather than developmental. Although cognitive deficits are present in many if not all mental disorders…, only disorders whose core features are cognitive are included in the NCD category. The NCDs are those in which impaired cognition has not been present by birth or very early life, and thus represents a decline from a previously related level of functioning" (APA, 2013:591)

Of particular interest here is the clear lack of any debate on this recently published classification system, as it makes a number of significant changes in disease classifications. Of note, dementia is now subsumed under the newly named entity 'major neurocognitive disorders' (NCD) – a new category of mental disorder where types of dementia appear almost secondary to the accompanying NCD. Alzheimer's Disease is now termed 'Major or Mild Neurocognitive Disorder due to Alzheimer's Disease'; 'Frontotemporal lobe dementia has become 'Major or Mild Frontotemporal Neurocognitive Disorder'; Dementia with Lewy Bodies is 'Major or Mild Neurocognitive Disorder with Lewy Bodies'; and, Vascular Dementia is now 'Major or Mild Vascular Neurocognitive Disorder'. Crucially, and surprisingly receiving little academic discussion, is the drop in the term 'dementia' from these four common types of dementia. What is even more remarkable is the number of other conditions that now fall within this same disease spectrum such as 'Major or Mild Neurocognitive Disorder due to Traumatic Brain Injury' and 'Substance/Medication-Induced Major or Mild Neurocognitive Disorder' – conditions which one would not usually associate with dementia like conditions. How this affects use of both the term and more importantly the concept of 'dementia' is yet to be realised. Also too, as we await the publication of the new ICD-11 it will be of clear sociological interest how World Health Organisation reconfigure its own definition of dementia and in its attempts to categorise.

From the perspective of problematization, the severity of dementia is assessed by cognitive levels, not mental health symptoms or brain pathology (histopathological findings, CT, SPECT or MRI scans). Commonly used cognitive scales in this area include the GBS Scale (Brane, 1989); Global Deterioration

Scale for Assessment of primary Degenerative Dementia (Reisberg, *et al.,* 1982); Mini-Mental State Examination (Folstein, *et al.,* 1975); and the Sandoz Clinical Assessment-Geriatric Scale (SCAG) (Shader, *et al.,* 1974). Many of these cognitive scales are possible because of the early ideas of Roth and Hopkins (1953), who saw questions about memory, orientation and attention as the starting point for quantifiable neuropsychological testing. This created a system of possibility that supported ways to think of dementia in this way.

A cognitive model of understanding dementia however can also be traced back in the *Archive* to Babcock's (1930) idea on using resilience of vocabulary scores to measure pre-morbid intelligence. The basis of this idea is still used, in an adapted form, today. A further *Archive* document by Botwinick and Birren (1951) also shows conditions of possibility in thought that declines in intelligence scores as noted in senile dementia were not the same as noted in ageing. This study represents an important discontinuity in thought, separating the understanding of dementia as a natural consequence of ageing to instead a cognitive conceptualisation, and allowed for the development of a host of test batteries. Some of these are detailed in Table 10 below:

Table 10: Test batteries for cognitive functioning

Date	Cognitive assessment	Authors	First published in
1952	Face-Hand Test	Fink, *et al.,* (1952)	*Neurology*
1958	Trail Making Test	Reitan (1958)	*Perceptual and Motor Skills*
1960	Mental Status Questionnaire (MSQ)/ Face-Hand Test (FHT)	Kahn, *et al.,* (1960)	*American Journal of Psychology*
1968	Blessed Dementia Scale	Blessed, *et al.,* (1968)	*British Journal of Psychiatry*
1972	Mental Test Score (MTS)/Abbreviated Mental Test Score (AMTS)	Hodkinson (1972)	*Age and Ageing*
1972	SET Test	Isaacs and Akhtar (1972)	*Age and Ageing*

1973	Buschke Selective Reminding Test	Buschke (1973)	*Journal of Verbal Learning and Verbal Behaviour*
1975	Mini-Mental State Examination (MMSE)	Folstein, *et al.,* (1975)	*Journal of Psychiatric Research*
1976	Mattis Dementia Rating Scale	Mattis (1976)	*Geriatric Psychiatry: a handbook for psychiatrist and primary care physicians*
1977	Cognitive Capacity Screening Examination	Jacobs, *et al.,* (1977)	*Annals of Internal Medicine*
1978	Kew Cognitive Test	Hare (1978)	*British Medical Journal*
1979	Clifton Assessment Procedures for the Elderly (CAPE)	Pattie and Gilleard (1979)	*Manual of the Clifton Assessment Procedures for the Elderly*
1982	Short Mental Status Questionnaire	Robertson, *et al.,* (1982)	*Canadian Journal on Ageing*
1983	Short Orientation-Memory-Concentration Test	Katzman, *et al.,* (1983)	*American Journal of Psychiatry*
1984	Alzheimer's Disease Assessment Scale (ADAS) – Cognitive and Non-cognitive Sections (ADAS.Cog, ADAS.Non-Cog)	Rosen, *et al.,* (1984)	*American Journal of Psychiatry*
1984	Stroop Color-Word Test	Koss, *et al.,* (1984)	*International Journal of Neuroscience*
1986	Clock Drawing Test	Shulman, *et al.,* (1986)	*International Journal of Geriatric Psychiatry*
1987	The Modified MMSE (3MS) Examination	Teng (1987)	*Journal of Clinical Psychiatry*
1988	The Telephone Interview for Cognitive Status	Brandt, *et al.,* (1988)	*Neuropsychiatry, Neuropsychology and Behavioural Neurology*
1989	Clock Drawing Test	Sunderland, *et al.,* (1989)	*International Journal of Geriatric Psychiatry*

1989	Clock Drawing Test	Wolf-Klein, *et al.,* (1989)	*Journal of the American Geriatrics Society*
1989	Syndrom Kurztest (SKT)	Erzigkeit (1989)	*Diagnosis and treatment of senile dementia*
1989	Boston Naming Test	White Williams, *et al.,* (1989)	*Neuropsychologia*
1990	Severe Impairment Battery (SIB)	Saxton, *et al.,* (1990)	*Psychological Assessment*
1991	Cognitive Drug Research Assessment System (COGDRAS)	Simpson, *et al.,* (1991)	*International Journal of Geriatric Psychiatry*
1991	Objective Assessment of Praxis	Connelly and Jamieson (1991)	*International Journal of Geriatric Psychiatry*
1991	Standardized Mini-Mental State Examination (SMMSE)	Molloy, *et al.,* (1991)	*American Journal of Psychiatry*
1992	The Test for Severe Impairment (TSI)	Albert and Cohen (1992)	*Journal of the American Geriatrics Society*
1993	Computerized Cognitive Examination of the Elderly (ECO)	Ritchie, *et al.,* (1993)	*International Journal of Geriatric Psychiatry*
1993	Wisconsin Card Sorting Test	Heaton, *et al.,* (1993)	*Clinical Neuropsychologist*
1994	Cognitive Abilities Screening Instrument (CASI)	Teng, *et al.,* (1994)	*International Psychogeriatrics*
1994	Revised Hasegawa's Dementia Scale (HDS-R)	Imai and Hasegawa (1994)	*Journal Of Hong Kong College of Psychiatry*
1994	The Ten-Point Clock Test	Manos and Wu (1994)	*International Journal of Psychiatry in Medicine*
1996	Stepwise Comparative Status Analysis (STEP)	Wallin, *et al.,* (1996)	*Journal of Geriatric Psychiatry and Neurology*
1997	Clock Drawing Test	Brodaty and Moore (1997)	*International Journal of Geriatric Psychiatry*
1997	Structured Telephone Interview for Dementia Assessment (STIDA)	Go, *et al.,* (1997)	*Journal of Geriatric Psychiatry and Neurology*

1998	7-minute Neurocognitive Screening Battery	Solomon, *et al.,* (1998)	*Archives of Neurology*
1998	The Time and Change Test: a simple screening test for dementia	Inouye, *et al.,* (1998)	*Journal of Gerontology*
1999	Memory Impairment Screen	Buschke, *et al.,* (1999)	*Neurology*
2000	A Cognitive Screening Battery for Dementia in the Elderly	Jacqmin-Gadda, *et al.,* (2000)	*Journal of Clinical Epidemiology*
2000	Lay Person-Based Screening for Early Detection of Alzheimer's Disease	Mundt, *et al.,* (2000)	*Journal of Gerontology, psychological Sciences*
2000	Short and Sweet Screening Instrument (SAS-SI)	Belle, *et al.,* (2000)	*Neuroepidemiology*
2000	The General Practitioner Assessment of Cognition (GPCOG)	Brodaty, *et al.,* (2000)	*Journal of the American Geriatrics Society*
2000	The Severe MMSE	Harrell, *et al.,* (2000)	*Alzheimer Disease and Associated Disorders*
2001	The Mini-Cog	Scanlan and Borson (2001)	*International Journal of Geriatric Psychiatry*
2001	The Neuropsychological Impairment Scale – Senior (NIS-S)	O'Donnell (2001)	*Journal of Clinical Psychology*
2005	The Montreal Cognitive Assessment (MoCA)	Nasreddine, *et al.,* (2005)	*Journal of the American Geriatric Society*
2006	The Addenbrooke's Cognitive Examination Revised (ACE-R)	Mioshi, *et al.,* (2006)	*International Journal of Geriatric Psychiatry*
2007	CANTAB (an automated neuropsychological test battery)	Égerházi, *et al.,* (2007)	*Progression in Psychopharmacology and Biological Psychology*

An important consideration, however, is understanding the knowledge underpinning the construction of these tests, often based on some degree or form

of factor analytical procedures. This can be traced to the work of Spearman (1904) who developed the two-factor theory of intellectual or cognitive functioning (commonly understand as ‘g’ for general intelligence and‘s’ for specific intelligence). Spearman’s work led him to the conclusion that general intelligence (g) was not affected by age-related decline. Rather, age-related cognitive decline was related to specific intelligence, specifically, retentivity (Spearman, 1927). Importantly, this idea of general intelligence was used by many clinicians to support the idea that a single general intelligence capacity existed which, when damaged by cerebral or brain disease, caused problems with intelligence. Although it may appear logical now, the relationship between brain damage and cognitive impairment was an important change to natural ageing arguments. When applied to dementia the *Archive* finds the work of Zangwill (1964) who argued:

> “The central issue in dementia is that of intelligence” (1964:32).

The problematization of dementia as a neuro-cognitive disorder provided a new way to speak about dementia. This is allows the language of the psychologist to be utilized in describing the symptoms and categorising dementia, importantly providing legitimization and growth for disciplinary power and control over dementia for this profession. However a contemporary observation born from clinical practice here needs to be made. If dementia is so re-conceptualised (and thus problematized) as a neuro-cognitive disorder, how is this then seen in practice? Interestingly we have a lens, a gaze, an ability to see dementia and speak of it in a particular way. The knowledge and the truth one may say is evident, but this gaze has been quicker than the social apparatus needed to maintain it. Indeed we may have the language of psychology at our disposal but we don’t have the psychologists. Knowledge and truth in this sense is devoid of any real power as systems of thought are yet to be enshrined within systems of practice. The social apparatus is only partly constructed. Disciplinary power for the psychologist has failed to materialise. Psychiatry and not psychology still remain in-charge. We discussed earlier in this section that the neuro-cognitive conceptualisation was born out from a hyper-cognitive Westernised society. Thus

its categorisation created problematization too. If beliefs however are maintained that the cognitive decline is inevitable, and that whatever methods are put in place degeneration would still occur, then how beneficial (or economical) would cognitive support practically become? Rather what we see is a solution in our hyper-cognitive society as one of containment (and I would suggest cognitive abandonment). Rather than saying the social apparatus needs to catch up with knowledge and truth, we actually see a more powerful undertone. The social apparatus has caught up, it has judged, and it has used its power to exert control to contain dementia within the field of psychiatry. The advent of 'neuro-psychiatry' as a sub-discipline in the care management of dementia however is the only sign of any continuity in thought.

This idea of containment and disempowerment has many similarities with disability and disability studies. This is interesting for with this increasing power struggle, between the person with dementia and society, we find from the *Archive* a very different form of gaze being created – to see a person with dementia as having a disability. If dementia is conceptualised as a disability then the focus or gaze is turned back, away from the person with the condition, but back on to society. Here we find it is society, whether as individuals, groups, institutions or communities that instead give rise to the repressing conditions of the disease and magnify its symptoms. This conceptualisation, dementia as a disability, is the subject of our next section.

5.3.5 Dementia as a disability and chronic health or long term health condition

Following a growing focus on social models to disability as a direct reaction to concerns regarding the over medicalisation of disability and the social barriers in place (based on the work of Oliver (1983) and the Union of the Physically Impaired Against Segregation (UPIAS) (1976)) the *Archive* presents an emerging discourse in applying these principles to dementia (Beattie, *et al.,* 2005;

Blackman, *et al.,* 2003; Boyle, 2014; Brittain, *et al.,* 2010; Davies, *et al.,* 2009; Dorenlot, 2005; Proctor, 2001).

Interestingly, it was during the 1980s that 'disability studies' began to grow (Barnes, 2012), to now also include a range of other long-term conditions other than its original focus on physical disability, including for example mental illness (Beresford, 2002). As noted by Oliver (2004),

> "The social model of disability is about… a clear focus on the economic, environmental and cultural barriers encountered by people who are viewed by others as having some form of impairment – whether physical, mental or intellectual" (Oliver, 2004: 21).

However, given the rapid growth of disability studies, it is of interest to note that 'dementia' as a topic for disability discourse is still relatively low and even still a marginalised construct. It is too early to speak of a clear sub-discipline of dementia within disability studies, but a start has certainly been made. Here we see the burgeoning growth of a system of knowledge that may yet go on to yield greater results in the future. Although marginalised as a discourse, its existence cannot be denied. A clear alternative to purely mental disorder or bio-medical conceptualisations exists and a new lens can now be held.

An important element of this conceptualisation of dementia as a disability is to provide clarity between the effects of society in 'disabling' dementia, and the unavoidable symptoms of dementia that situate it as a disease. This critique is crucial if one is to argue the legitimisation of this new concept. To support such a view the *Archive* provides the work of Thomas (1999) who introduced the idea of 'impairment effects'. In a later publication, found in the *Archive,* this idea was further developed to include;

> "The direct and unavoidable impacts that impairments (physical, sensory, intellectual, emotional) have on an individuals embodied functioning in the social world. Impairments and impairment effects are always bio-social and culturally constructed in character" (Thomas, 2010:37).

Thus it is important to understand that dementia as a disease will produce impairments that ought not to be considered consequences of disability and social models. Classically these are referred to as symptoms of dementia.

In understanding the disability concept, we need also to understand the social factors at play. Importantly we find a clear departure here from Southard's (1910) claim that

> "[There is] little convincing evidence that social factors play much part in [dementia]... cases. Whatever the cause of brain atrophy, it seems that they cannot be social" (1910:673).

This then alludes to the role of person-centred care philosophies – an approach which our *Archive* finds in the work of Kitwood (1997), who introduced this approach as providing an alternative to traditional bio-medical models. This focus on person-centred care is however not new, and did not start with Kitwood as most dementia histories appear to suggest. Our *Archive* notes that Pinel (1801, 1816) provides one of the first recorded attempts to understand the patients experience in considering life events and psycho-social implications that may have precipitated the condition. This conceptualisation was expanded over a century later, by Rothschild (1937), who considered emotional and personal difficulties faced by people with Alzheimer's disease. He noted in particular the contradictory findings evident in repeated post mortem cases that the pathological results did not always equate to behaviour patterns noted, thus arguing for an early psycho-social understanding.

Another major impact of Rothschild work was changing perception of dementia and arguing that society itself has a great impact on the experiences of people with dementia and their symptoms. Almost 30 years later, research by Ross, *et al.,* (1966) also noted that despite finding the number of plaques and tangles in the brain equated to severity of behavioural symptoms, that importantly the same plaques and tangles were also noted post-mortem in a number of people who were not diagnosed as having dementia.

A growing demand then for person-centred care as a core element of dementia practice with its clear focus to divert away from bio-medical reasoning to instead consider the impact of social–psychological forces is advancing. To understand dementia in this latter way we are moving steadily away from mental disorder and biomedical concepts to rather disability models and chronic ill health pathways,

with a social model of disability in particular gaining momentum (see Gilliard, *et al.,* 2005). Two recent publications contained within our *Archive*, one by the Joseph Rowntree Foundation (Thomas and Milligan, 2015) *How Can and Should UK Society Adjust to Dementia?* And the second, by the Mental Health Foundation (2015) *Dementia, Rights, and the Social Model of Disability: A New Direction for Policy and Practice?* Echo these very thoughts. Both reports reflect on an ever growing desire and move to apply a social model of disability to dementia care. Thus then we are currently faced with a conceptual dichotomy, an idea alluded to in our introductory chapter, that of *mental disorder or disability*, with the answer presumably lying partly with each.

Acknowledging the consequences of dementia may well have led to the beginnings of its conceptualisation as a chronic condition. Following a growing body of support provided by dementia lobbyists and advocacy groups a number of large and influential organisations became to be formed in Western societies, two American: the National Institute of Ageing (NIA), Alzheimer's Disease and Related Disorders Association (ADRDA), and one British: the Medical Research Council (MRC), who latterly although formed much earlier, did in 1977 make dementia a priority area. This is an important consideration for, as Fox (1989) notes, such as rise in activist interest is likely to have a profound effect of the marketability of the disease. This clearly economic interest in dementia, and one likely to support investment in treatment and management is surely a guiding condition for conceptualising the disease. This was important for it spurred further discussion leading to renewed interest from 'service users' including carers of people with dementia. Surprisingly, it would seem, despite the optimism created by psycho-social and cognitive conceptualisations, carers seem to want something different – a demand for a focus on finding a cure for dementia.

An interesting, and under-recognised discussion of disability and chronic illness conceptualisations of dementia that warrants consideration is that of genetics, previously discussed in our section on bio-medical concepts. There is a risk of seeing disability perspectives as purely social models, but it is important to recognise to that a large percentage of people with a disability also may have a

genetic condition. This interplay, the genetics of disability and long term conditions, should therefore also be accounted for within such a perspective and is a good example of the interplay and overlap that exists between biomedical discourse and disability discourse – thus actually questioning Kitwood's 'alternative approach' idea. Roth (1994) was keen for example to acknowledge the role of genetics in accounting for why some people may or may not develop Alzheimer's disease. This provides some clear links between disability and social models and once again bio-medical models. Recent developments on Dementia Friendly Communities, Dementia Action Alliance, and also dementia friendly services and environmental design are rapidly growing pace. Whether it be to change the environment or to change the approach, either way, the change here is with the 'other'. The gaze is not then on the person with the dementia, they are no longer the ones that are being problematized. The gaze instead is on society itself. The society that sought to create the social apparatus is now itself under its own scrutiny.

5.3.6 Dementia as a terminal illness

Our sixth and final finding is dementia conceptualised as a terminal illness. Our *Archive* shows there are clear signs of a growing interest in the palliative and end of life care for people with dementia supporting the need to recognise dementia as a terminal illness (Davies and Higginson, 2004; DH, 2008; DH, 2009; DH, 2012). A clear feature of dementia is that it is a progressive disorder resulting in a continued deterioration in functioning, with our *Archive* finding authors such as Reisberg, *et al.,* (2006) arguing that the middle/late stages of the disease actually mark the beginning of an extended and intensive palliative care stage. Importantly these authors note that the duration of this stage is double that of the early stage. This palliative stage is thus being recognised as a cardinal element of the condition, so much so that 'dying well' (Lawrence, *et al.,* 2011) just as much as 'living well' (DH, 2009) with dementia become how one speaks about the experience of dementia. Interestingly this is a marked change from the disability model where the focus was 'living well'.

The *Archive* shows that discussions surrounding the end stage of dementia however are not new, with some early documents showing a need to enter in discussion about this stage:

> "Death, in dementia may occur from the supervention of various acute or chronic disease, having no immediate connexion with the brain; or it may apparently depend upon the cerebral affection, life being terminated by an apoplectic seizure, or the slow progress of paralysis" (Wood, 1855:664).

However closer examination of this text reveals that rather than looking at the terminal prospects of dementia, the focus instead lies on how people with dementia die. Death was acknowledged but our framework analysis method found this was not actually seen as a part of dementia itself. In this sense it wasn't a 'stage' of dementia, rather a natural consequence of any disease process and thus not warranting any special consideration.

To speak of dementia as a terminal illness thus did need to wait until the early twenty-first century. But what were the conditions of possibility that allowed dementia to be discussed in this way? Interestingly at this time a growth in medicine saw developments in palliative care and the growth of hospice care. Additionally a growth in professions and the creation of the Macmillan and the Marie Curie nurse heralded this move. Gradually the developments found in traditional palliative care then slowly began to be applied to end stage dementia, however it would still be many years forward until hospices began to open their doors to patients with dementia and that the current dementia nurse specialist in the UK, the Admiral Nurse, also began to spread away from the community mental health teams to also acute hospitals and then to hospices. What we are in fact speaking of is a dramatic departure from classical psychiatric problematization to instead notions of physical co-morbidity and frailty. In this way one can also see links being made between, ironically, the first and last of our discovered conceptualisations – that of older age and of terminal illness.

Our *Archive* notes one of the key turning points in discourse that saw a differentiation in the problematization of dementia from psychiatric to palliative

responsibility came from Mitchell *et al.,* (2009), described by the media at the time as;

> "the first study to rigorously describe the clinical course of advanced dementia, a leading cause of death among Americans, researchers in the US concluded that dementia is a terminal illness and is insufficiently recognized as such, resulting in many patients not receiving the palliative care that aims to improve the comfort of the terminally ill" (Paddock, 2009; online).

The study by Mitchell and the associated media reactions interestingly depict it, as quoted above as 'the first study to rigorously describe…' This statement draws on the quality, validity and rigour of the research in a way to make the general public take notice – its dissemination. As noted Sachs (2009) further commenting on this article in an Editorial noted it:

> "Moves the field forward in major ways with regard to prognosis and the terminal nature of advanced dementia" (Sachs, 2009:1595).

Thus it was this discourse, contemplated because of the growing demands of physical complexities and thus the potential financial as well as moral implications, and the then consequent media reaction to the results that prompted the growth of a new conceptualisation of dementia. Importantly, this also required a new type of professional, competent in understanding the terminal nature and the associated clinical complications to be created. The focus on psychiatry and mental health nursing is thus eroded and replaced with skilled professionals competent in nursing patients with pneumonia, febrile episodes, malnutrition, seizures, gastrointestinal bleeds, hip fractures, stroke, pulmonary embolus, myocardial infarction, dyspnoea, pain, pressure ulcers, aspiration, agitation, and the management of palliative symptoms. Adult nurses become the field of practice choice, whose skills and education are most clearly adapted for providing this required type of assessment and intervention. Thus, we see that the present conceptualisation for dementia as a terminal illness was not created until the twenty-first century, and the kind of person with dementia has now changed to a kind of person with a terminal illness in whose clinical course will result in a potential myriad of clinical complications and other physically distressing symptoms. The emphasis here is the physical and not the mental. Thus, to be a

kind of person with dementia is no longer to be a kind of person with a mental disorder, rather it is to be a person with a terminal illness.

5.4 Summary

The main focus of this chapter was to provide a genealogical account of dementia. In this sense it un-picked how dementia has come to be problematized in Western society and situated within a complex power/knowledge social apparatus. It is this systematic attempt at problematization through discursive practices that create, and are created by, transformations in power and knowledge and thus departs from traditional histories of dementia. In this sense it has demonstrated how the concept of dementia has been created and recreated, showing too how the privileged position of psychiatry and mental health as a discipline to manage dementia was made possible, as well as the current ruptures and cracks that are again starting to show. In essence this chapter has shown how we speak of and about dementia, thus offering a genealogy of dementia, not just another total history based on periodization.

The following ruptures and discontinuities of thought can be taken from this genealogy:

- That although dementia may not be seen as a normal part of the ageing process, there is a growing body of evidence looking at pathophysiology in people aged over 80 years of age, which may give more contemporary support to this idea.
- That there are clear examples of dementia associated pathology, but the presence or otherwise of this is not sufficient to explain dementia.
- That there are neuro-cognitive explanations that may present a more reliable explanation then the bio-medical model, but that the presence of other lifestyle factors may compound these results.
- That understanding dementia as a long term chronic condition and a disability is a relatively new understanding, based on person-centred principles, but that such notions do not fully support the gravity of

experience and ‘suffering’ felt by people with this condition and their carers.

- That an alternative idea is slowly gaining interest, and seeks to follow the journey from beginning to end of what is taken to be a deteriorating neurological disease, necessitating the need to focus on the presenting symptoms and experience.

Professionals will have their own disciplinary assumptions about dementia. As noted by Lock (2013), such groups may have at best partial connections with other groups whereupon, even at major conferences, experts would only attend those sessions they feel of relevance to their specialism. As we move between differing conceptualisations of dementia we need to consider the way in which such tensions become evident and at which point they meet. One example of the latter may be provided by Richards and Brayne (2010) who in recognising the lack of agreement and consensus on what amounts or not to dementia, argued in their article entitled ‘What do we mean?’

> “No straightforward correspondence exists between higher mental function and the burden of lesions in the ageing brain. If this shifts the focus away from detailed diagnostic classification made on the basis of assumed clinical-pathological correlation and towards a global pragmatic approach to the needs of patients and carers, and to modifiable lifetime factors, then the apparent loss of scientific precision is a gain to clinical practice.” (2010:866)

Six tensions are brought into discussion. Notably the direction seems to move away from the clinicopathological and scientific classifications to a more ‘holistic’ conception of need. If the concept of need is used to guide understanding then the moving into disability understandings and the burgeoning terminal illness concept, our next big rupture, seems to offer much thought.

However, what may appear on the surface to be six different conceptualisations, each having undergone their own systematic transformations, is something different. In fact they all remain discursively linked as manifestations of a shared system of thought in which power and knowledge become embedded - the savoir and the connaisance. What we find from these shared ideas is that dementia has

been created, recreated and is currently undergoing yet another new conceptualisation with a wholly new, and currently un-critiqued, discourse that leads to its problematization in Western society. Importantly this has shown that one cannot speak of dementia as an entity independent of the social apparatus that governs its normativity or the existing possibilities of thought. This provides constitution of the dementia subject as subject to change and re-constitution.

Understanding dementia, including how, and in what way, it has become a subject for nurse education can no longer be seen as definitive. Importantly what dementia is taught to be, or its constitution, is merely the product of today's psychiatric *gaze,* but is one that also remains subject to reconstitution. Shifts in this gaze have been noted from natural consequences of normal ageing to bio-medicalization, from disability models to terminal illness models, depending on its problematization and thus demonstrate conceptual attitudes that move from the physiological and biological to an understanding of the psycho-social and frailty.

One other interesting point here is whether our differing conceptualisations actually refer to conceptualisations of the disease progression or the dementia journey. Although at different eras our *Archive* shows conceptualisations change, focusing on different elements, and then disappear before again re-emerging. What we are actually seeing are changes in the problematization of a progressive disorder – differing 'stages' of dementia being see more or less of a problem at different points in time. This idea makes sense when considering social climates of spending, budgets, economic climate, *etc*. Rather than seeing differing ways of seeing dementia, we are instead just seeing one element at a time rather than the whole picture. These become glimpses of what the *Archive* reveals, and are in effect the consequences or outcomes of power/knowledge dynamics. Indeed what our *Archive* has shown is that conceptualisations, although split into six clear themes, are interwoven. This interweaving is not because of a lack of specificity or agreement, or conflict between professionals and the like, but rather because it remains one and the same thing. We need to clearly ask, given the six different ways dementia has been conceptualised, which is to be accepted. This then calls

into question how a person can be made up, to be a type of human kind, and in this context and of importance, what it is then to be a person with dementia.

Chapter 6: Discussion

6.1 Introduction

This chapter provides a context, based around Foucauldian principles, in which the findings can be more fully applied. It begins with a discussion surrounding the justification and the importance of applying a socio-history and genealogy enquiry, and the need to look at the past in order to fully understand the present. In this sense, the history of the problematization of dementia is necessary to understand the way we see dementia today. Drawing on the work of both Foucault (1977[1975], 1978[1976], 1984, 1989a, 1989b), and Hacking (1986, 1996, 2007), this is then applied to dementia education and research. Here we consider how we come to see dementia through its problematization (Foucault, 1984), and then how this has a direct 'looping effect' (Hacking, 1996) on how dementia care is organised. This then leads to the 'making up of people' (Hacking, 1986) with dementia – effectively what it is to be a kind of person with dementia. We place this into context, by addressing the Foucauldian principles of power, knowledge and truth at work (Foucault, 1983, 1989a, 1997), particularly considering the interplay of *connaisance* (surface knowledge) and *savoir* (depth knowledge). Finally this discussion chapter poses a potential critique of the approach used in this study and the potential for the underestimation for other conceptualisations to exist. In addition, how others may use alternative labels to that chosen in this study to frame our concepts and how these areas may come and go at different times. In particular, it discusses the principles of understanding Western society as based on Judaeo-Christian beliefs and both the interpretive and the methodological consequences that this study may be subject to.

6.2 The socio-history and genealogy of dementia

Ackerknecht and Vallois (1956) once wrote that if any 'science' is to chart new and reliable paths, then it must also be able to re-examine its essential premises

that are best understood by studying its origins. The same can be applied today, regarding our understanding of health science. Here then, to understand the progress of dementia in the health sciences, a knowledge of its origins or history is thus, argued to be important. It is only through this type of enquiry, looking at our past, that we can informatively know and thus, make sense of both where we are, and where we are going. This then must lie at the heart of professional practice for nurses, educationalists and researchers in dementia care/research.

However, a total history based on periodization as found in a number of other reported histories (e.g. Amaducci *et al.,* 1986; Boller, 2008; Boller and Forbers, 1998; Brannon, 1994; Cipriani *et al.,* 2011; Porter, 1995; Torack, 1983), is not sufficient for the purposes of this enquiry and we must be clear that this study has not then been a history of dementia in this sense (i.e. a total history), but rather a type of socio-history, a general history, of what it is to be a person with dementia. This relates to how the condition came to be, and the effect this had on audiences wider than that of the self, for it is this 'concept' of dementia that will then become the subject of nurse education and research programmes. As changing concepts of what it was to be a person with dementia developed, then so did its education to the professionals 'designed' to provide care and support. Thus, our study needs to develop into this wider realm and apply its lens to how dementia became constructed and re-constructed over time and to analyse how this may have taken place. Further, we must consider both current and future trends in this area. This has become the foundation on which this study rests and importantly, takes it further than the limits of a total history, as depicted in the traditional dementia literature seen in the our literature review chapter. It asks instead to consider the power, knowledge and truth at work. Here then we recognise the creation of a socio-history and an important genealogy of dementia conceptualisation.

In this sense dementia education and research can only be understood as a conceptualisation of what it is to be a person with dementia at a particular moment in time. This is dependent on the social apparatus and systems of knowledge allowing such discourse to be maintained. Dementia education (Pulsford et al., 2007) and in particular curricula content (HEDN, 2013; Skills for Care/Skills for

Health, 2011) thus, can only be understood as a product of the prevailing dementia 'discourse', and it is through the careful interrogation of this discourse, including its past and present, that we may possibly also find where its future lies.

The history of dementia as we have seen, is abundant in politics and scientific discoveries. However, a systematic unearthing of the socio-historical ideas surrounding dementia has demonstrated that there is a need to further understand the emerging thoughts and events of the time (Ballenger et al., 1999; Ballenger, 2006; Davis, 2004). Here we find ourselves considering ideas that may otherwise go un-noticed, to which we then can make a possible series of connections, out of which our contemporary conceptualisation of dementia in Western society becomes formed. The result of which then for this study is the first orderly structure of ontological reasoning in this area.

What this study has attempted to do, was to bridge across both traditional history and sociology (Abrams, 1982) and to look at the problematization (Foucault, 1984) of dementia. This approach showed how our understanding and conceptualisation of this disease has come to be shaped. This study develops the original work of writers such as Davis (2004) and Ballenger (2006) by further examining how the problematization of dementia arose within a socio-historical context. This included examining the ways in which this came to be shaped, changed and then added to through a series of dominant and subjugated discourse practices, leading to the creation of ways of seeing dementia. This adding then also to the work of Downs *et al.,* (2006). It is through this we can then begin to speak of and map out its problematization in Western society.

6.3 The problematization of dementia

For nurse educationalists and dementia researchers, knowing the changing problematization of dementia and how this has shaped, not only what it is to be a person with dementia, but also and as equally significant, the key professionals who then need to be called upon, is important. This is best illustrated with the latter conceptualisation identified dementia as a terminal illness (Wolf-Klein, *et*

al., 2007). This has the potential of shifting the focus from mental health nursing, and the key professionals involved in old age psychiatry (as noted by Downs *et al.,* 2006) to instead, adult nursing, hospice care and supporting people to die well with dementia (Davies, *et al.,* 2004; DH, 2009; Jordan, *et al.,* 2012; Pinzon, *et al.,* 2013; Sampson *et al.,* 2009; Simard, 2013; WHO, 2004; Wolf-Klein *et al.,* 2007). Here we see a refocus from behavioural and psychological symptoms to instead communication, advance care planning (Dening *et al.,* 2011), pain assessment and control (Abbey *et al.,* 2004; Jordan *et al.,* 2012), and palliative symptom management (Hendriks *et al.,* 2014). As the way of seeing dementia is subtly transformed in this way, then so too is the need to provide a skilled workforce able to work within these newer conceptualisations (Skills for Care/Skills for Health, 2011). Here, mental health nurse training would require greater awareness of end-of-life care and in particular recognising signs that herald the beginning of palliative stages, so optimal care and/or sign posting can be provided. So too however, adult nurse training must be developed to consider people with dementia and their carers, including best interests and capacity assessments, advanced communication skills, pain assessments and working closely with carers. This will be best realised when hospices begin to open their doors in greater numbers to people with dementia (Volicer, 1986). Interestingly, in using this one example of a re-problematization discourse in dementia care, we see a potential for shaping assumptions or constructs that may have otherwise been constraining the ways in which dementia can be seen; what it is to be a kind of person with dementia (Hacking, 2007).

Moving then from giving one example to a more overall perspective of this study, we see provision for introducing an overarching conceptual map, in understanding how people with dementia are made up (what it is to be a kind of person with dementia) and the kinds of professionals required to (Hacking, 1986, 1996) provide care and support. Our understanding of the past will therefore suggest how dementia can come to be problematized in a particular given way and thus, provide us with clues as to how we can educate our future nurses and direct our dementia research agendas.

6.4 Power, knowledge and truth

The analysis of the *Archive* employed the principles of a post-structuralist, or more specifically, a Foucauldian approach. This was a deliberate methodological choice, that proved advantageous because in the same way Michel Foucault (1967 [1961]) in *Madness and Civilization* started with the tenuous belief that 'madness' may be a pure thing, unable to be captured as a concept, this study suggested a similar early presumption existed with 'dementia' (e.g. Pinel (1818); Esquirol (1805, 1814); Kraeplin (1912 [1904], 1910; Blumer, 1907; Torack, 1983). However, this study found dementia is counted, classified and then treated, through systems of 'societal creation' (Harding and Palfrey, 1997; Innes, 2009). Similar to how Foucault found 'madness', this study also found in dementia that the social apparatus and systems of knowledge and thought that permeate Western society created, and continues to shape and challenge, the terms to which dementia is conceptualised. Drawing on this Foucauldian enquiry, quoted in a 1977 interview, Foucault began to question some of his initial basic assumptions in *Madness and Civilisation* (1967 [1961]) and *Birth of the Clinic* (1973 [1963]:115). He noted;

> "When I think back now, I ask myself what else it was that I was thinking about… but power?"

This was because *Madness and Civilisation* (Foucault, 1967[1961]) essentially saw the exercise of power as repression, although his later works go on to reject this idea, where instead he began to argue that power needs to be linked to knowledge.

Applied to this study, psychiatrists and pressure groups, *etc*. throughout the history of dementia have emerged to form a band of growing dementia subject experts. Coupled with a varying degree of hypotheses and prejudices, constantly revised through time, there remained an underlying conception of dementia either as a natural consequence of ageing (Nascher, 1911, 1914, 1915; Creasey and Rapport, 1985; Critchley, 1931), psychiatric disorder (Bleuler, 1925; Zangwill,

1964), long term condition/ disability (Thomas and Milligan, 2015), neurocognitive disorder (Barfus *et al.,* 1982; Drachman and Leavitt, 1974; APA, 2013), or terminal illness (Wolf-Klein *et al.,* 2007). In Foucauldian terms this represented the '*connaisance*' or surface knowledge to which '*savoir*' or depth knowledge, is then applied. *Savoir* constitutes the kinds of thought that are going to count as true or false within a range of emerging and differing areas. In the same way that Foucault argued the kinds of thinking used for the brain in 1780 were not the kinds of thinking to be observed a quarter-century later (Hacking, 2004), our *Archive* the same parallels can be made with dementia. This is because 'dementia,' through its socio-history denotes different kinds of objects and occurs in different ways of speaking – in Foucauldian terms, its *savoir*.

New knowledge about dementia can be directly linked to its liberation from old age, or senility. This permits dementia to be 'counted' as a disease rather than a 'natural consequence' of mental decline in old age. One important aspect of this is the nature and ontological status that then follows dementia as an independent phenomenon. It becomes a new 'kind' of person. Based on the work of Hacking (1996, 2007), this 'kind' is analogous to his depiction of human kinds that are peculiar to people in social settings. Becoming a 'kind of person with dementia' in this way means new things can be said and thought about dementia, differentiating it from other kinds of people, such as being a kind of older person or of being senile. This requires and draws upon those who establish themselves to be experts of this kind (dementia experts), akin to Foucault's (1973[1963]) *Birth of the Clinic* where a self-constituting class of experts, located within a new knowledge, are then formed. The study has shown that new kinds of professionals have developed in response to different conceptualisations, or problematizations, of dementia, as also noted in early research by Downs *et al.,* (2006). Most obvious is the move from 'geriatrician,' to 'psychiatrist,' to then 'neurologist'. Based on this trajectory, predictions that growth in health and social care practice outside of mental health would develop new types of professionals with expertise specialising in dementia. Applied to nursing practice, the only registered nurse specialist charity supporting people with dementia and their careers in the UK is the organisation Dementia UK who have currently 226 [at

the time of writing] Admiral Nurses (personal correspondence, Dementia UK). Admiral Nurse Posts were initially only given to registered mental health nurses. However in 2014 the first adult nurse became an Admiral Nurse, and then in 2015 the first learning disability nurse. This is interesting for it depicts movement away from 'mental disorder' to alternative ideas and conceptualisations. A new type of professional with expertise in dementia has been created. Differing problematizations, conceptualisations and changing discourse act in this way to change not only how dementia is conceptualised but also what it means to be a certain kind of person with dementia and thus the type of nurse or professional required to support their care. Another example of this found through this study are adult hospice nurses specializing in palliative care working in dementia care, following the problematization of dementia as a terminal illness. Changing conceptualisations come to bring about new kinds of person (with dementia), a new kind of professional (nurses other than mental health nurses providing care) and a new type of education/training curriculum (HEDN, 2013). A symbiotic interconnection between *discourses* that shapes the *kind* of *person* is created, and this in turn also shapes discourse. Discourse is shown to exert power, permitting /legitimizing, subjugating and side-lining how to speak of, and what it is to be, a person with dementia. This becomes the central issue in the socio-history of dementia, and is best understood through its archaeology and genealogy.

Rather than drawing on the development of science, as found in most historiographical research, one must instead look at the sentences of discourse, of how dementia came to be spoken of - its *connaisance* and *savoir*, producing the framework for our knowledge in conceptualising dementia. This first brings us to Foucault's *The Order of Things* (1970[1966]), the starting point of understanding the archaeology of dementia depicted in our *Archive*. This tells us of the age of reason, the renaissance, the nineteenth century and the future. *The Order of Things* is essentially about how one *savoir* can mutate into another and with what consequences. It is not then about periodization. The history of dementia does not evolve out of new discoveries, but rather from the coming into being of new objects of thought that in effect give rise to a range of different, or

new, truths for what actually could be said about dementia. In this sense, the history of dementia rather than following a traditional teleological or Whiggish scientific progress, needs instead to be seen as a history of discourse and problematization.

However, as argued by Foucault, discourse, or the class of sentences that can be uttered within a specified time and place is not actually determined by the conscious wish of the author, and thus, how we speak of dementia does not reside in the authors wishes. Consequently, from a Foucauldian perspective, the author becomes irrelevant to any such 'conditions of possibility,' leaving the discourse on dementia unable to be analysed in terms of who says what. Rather it is built on the systems of thought under which these sentences can be constructed and thus be are capable of being uttered. These conditions lie deep within the *savoir,* existing within specific time-frames, and including a multiplicity of systems of thought. The author here is merely then an actor speaking within the context and structure of the *savoir*, the systems of possibility of what can and cannot be said about dementia.

This provides an ontological imperative - the material conditions in which such sentences and discourse about dementia need to take place also require investigation. However, if there is to be a reluctance to refer to the author, the interest has to lie somewhere else. For Foucault this became a focus on the interests to which spoken words could serve (Hacking, 2004). In dementia, this has included an interest in the growth of psychiatry, which at the time of Alzheimer's discovery, was facing somewhat of a legitimacy crisis against the growing psychoanalytical theories and the science of clinical medicine (Ballenger, 2006; Davis, 2004; Innes, 2009). The twentieth century thus sought to re-classify mental disorders within pathophysiology, with dementia becoming a useful target. In 'inventing' Alzheimer's disease as an organic form of mental disorder, separating it from senile dementia (Kraeplin, 1910), influential discourse continued to remain undisturbed for accepting dementia as a normal part of ageing (Gowers, 1902; Byrnes, 1913; Nascher, 1914). It is concerns like this that

have come to shape this study's genealogy. Certain changes however, were shown to lead to new ways of thinking about dementia.

To count dementia as a psychiatric mental disorder meant that one ought to do something with this kind of person. This type of enquiry is less about the ideas of dementia, and rather concerns itself with the possibility of thinking about the 'kind' of person (Hacking, 1986) with dementia. This produces a gaze that fixes a type of problematization or conceptualisation about what dementia is, and ultimately affecting the fate of the individual with this condition and the type of professional required. The history of dementia as shown in this study suggests a basic plot of conceptualising dementia, with discourse following six main axes; i) Dementia as a natural consequence of normal ageing, ii) Dementia as an organic mental disorder, separate to normal ageing, iii) Dementia as a biomedical disorder, iv) Dementia as a neurocognitive disorder, v) Dementia as a disability and long term health condition, and finally vi) Dementia as a terminal illness.

The socio-history and genealogy of dementia presented in this study includes a certain positive knowledge of bureaucracy that counts and classifies people in accordance with the prevailing discourse of the time. Plum (1979) discussed the prospect of a dementia epidemic, and to follow was a surge in interest in 'counting' this kind of person. This interest during the twentieth century grew largely because new kinds of ideas about dementia could then be brought into consideration as things to be found out (Critchley, 1931; Hannah, 1936; Malamud and Lowenberg, 1929), and thus is linked to discourse on mental disorder (Lowenberg and Waggoner, 1934; Mayer-Gross, 1944; Roth and Hopkins, 1953), populated mainly by psychiatric medicine. Even as far back as the late 1980s, writers were once again arguing that 'dementia is once again a fashionable topic of investigation' (Berrios, 1987:829), a perception that still exists today. The twenty-first century, and particularly in the last five years, has seen a change in focus to disability rather than medical models, a view advocated by the Joseph Rowntree Foundation Publication (Thomas and Milligan, 2015). A new discourse is thus starting to emerge that challenges its psychiatrisation, focusing instead on the social model of care (Boyle, 2014; Mental Health Foundation, 2015; Shih-Yin

and Lewis, 2015) and gives us new ways of thinking and conditions of possibility. Dementia is once again going through an age of re-conceptualisation.

Power, formed within the discourse, exerts then new kinds of truths – the effect of these conditions of possibility and systems of knowledge that dictate what can and can't be said about dementia. Truth, Foucault argues is to be understood as a system of ordered procedures for the production, regulation, distribution and operation of statements. Truth is linked in a circular relation with systems of power which produce and sustain it. In this sense it is an abstract element that takes place deep within the *savoir* (Hacking, 2004). It is wrong however, to presume this power originates within psychiatric medicine, pressure group, or any other individual person or group alone. Rather a series of ideas or *connaisance* are built which, when combined, produce an overarching *savoir.* It is here, and not with psychiatric medicine, that knowledge, power and truth reside. This remains independent from the author of any discourse contained within the *Archive*, but it is one where the author resides and thus ultimately takes his/her direction. The disability movement, as suggested above, is one clear example of this and its effect on dementia is growing (Mental Health Foundation, 2015).

Foucault (1976) argues;

> "Let us not, therefore, ask why certain people want to dominate, what they seek, what is their overall strategy. Let us talk, instead, how things work at the level of on-going subjugation, at the level of those continuous and uninterrupted processes which subject our bodies, govern our gestures, dictate our behaviours, etc. In other words, rather than ask ourselves how the sovereign appears to us in lofty isolation, we should try to discover how it is that subjects are gradually, progressively, really and materially constituted through a multiplicity of organisms, forces, engines, materials, desires, thoughts, etc." (1976:97).

To understand the conceptualisation of dementia is thus also to understand how people with dementia themselves are constituted (see Boyle, 2014). Just as for Foucault there was, in the end, no pure madness, there is neither then any pure dementia, nothing-in-itself which we can objectively speak of that is independent and free from ever changing forms of description and action. Our *Archive* shows that no-one thought of themselves as a person with dementia as 'that' kind of

person, (as we today understand it), before it first had been medicalised. One just had failing memory and problems with judgement and reasoning as age progressed. It was a normal and natural part of the ageing process whereupon many people succumbed, particularly with advancing age (Barrough, 1583, Laurentius, 1599).

Nor was it an independent mental disorder. There were of course 'signs and symptoms' (although these terms are themselves part of a medicalised view of the world), but not a 'demented' *kind* of person as we know it today (Hacking, 1986). It was a normal sign of the ageing process. It was not a psychiatric disease that ought to be categorised and medically managed. Dementia only existed as a mental disorder at the point when the conditions were right, with the systems of thought, knowledge and possibility that would allow psychiatrists to classify it as such (Charcot, 1881; Day, 1849; Diderot D and d'Alembert, 1754; Morrison, 1839; Pinel, 1801; Pritchard, 1837; Rush, 1793) were in play. A system of knowledge/power so effectual that it permeates what it is to be a person with dementia still to the present day (Down's *et al.,* 2006). To be a 'kind' of person with dementia in contemporary society is then to be what the psychiatric professions judge it to be. This discourse is part of an overarching *savoir* that influences a range of other institutions too such as in the fictional literature, through the creative arts, Higher Education Institutes and the media/ press coverage, all of which come to effect what it is to be a kind of person with dementia today.

Given current trends however, we are led to a prediction that a new kind of person with dementia is also emerging, not one of old age/ senility or one with a mental disorder but instead as a kind of person with a disability and long term condition evidenced here by the increasing attention to person-centred care practices (Kitwood, 1997) and growth of dementia friendly communities (Shih-Yon and Lewis, 2015). The 'invention' of the Dementia Action Alliance may be seen as one clear example of this (Dementia Action Alliance, 2010).

Here then we can argue that despite the range of terms used over time to refer to dementia (amentia, imbecility, morosis, fatuitas, foolishness, stupidity, anoea,

simplicity, carus, idiocy, dotage and senility (Berrios, 1987)), it still seems to have maintained a sense of phenomenological stability. This refers to the general consistency of symptoms noted throughout the *Archive* for people with dementia, but less agreement on what these symptoms represent, what it is to be this kind of person. The kind of person, or rather what it is to be a person with dementia *has* changed and this is the finding of this study. Our genealogical enquiry finds that this change in what it is to be a person with dementia, occurred not as a result of scientific discovery, a concern also highlighted by Ballenger (2006), but rather as a result of its changing problematization. To understand dementia in this way is to embark then on new ways in constituting a history of problematization in Western society– the focus is on society, through its socio-history, and not the dementia.

The study finds the nature of dementia, including its ontological status, has for its 4,000 year history been the subject of concerted debate. Implicit within this study is whether or not being a person with dementia constitutes a specific kind of person. Each new way to think of a person with dementia, either as a person going through a normal part of the ageing process, a person with a mental disorder or with a disability, or as we then later find, as a terminal illness, is fundamentally a consequence of its problematization by society, determining what it is to be a kind of person with dementia. Each way in which a person is seen as a kind of person with dementia is in fact what has been constituted within and through its socio-history rather than the history of the disorder itself. A key finding of this study is that to understand dementia without understanding its history would be to render it a meaningless term.

6.5 Missing or alternative conceptualisations

Are there other conceptualisations that may so far have been left hidden deep within the *Archive* or even missed? In critical reflection, if I were to think how a condition may be conceptualised and then look for evidence (rather than the process adopted in this study which looked at the evidence first and to only draw

from that its findings) I might ask, what other forms of discourse might be possible? Western society for example has its own cultural and spiritual past as discussed in section 1.2 of this study, notably Judaeo-Christian origins. However a range of religions and spiritual belief patterns now also permeate Western society, what we noted in section 1.2 as inter-society minority communities, whose ideas may not be based on Judaeo-Christian beliefs and practices. This was outside the scope of this study and thus remains un-explored. However, the early history and foundations of Western society would likely have been dominated by the relationship between people and Judaeo-Christian beliefs in God. This relationship would come to affect whole systems of knowledge and of course power to control what can and what cannot be said needed and may suggest that alternative conceptualisations might also co-exist.

Although on the surface it would appear that the socio-history on the role of religion in dementia in Western society is left unexplored, this might not be entirely accurate. The effect of religion to contemporary discourse can be traced to the scholarly traditions of writers such as Tom Kitwood and Malcolm Goldsmith, both theologians by background, and both appearing in our *Archive.* Interestingly their contributions to our discourse both centre on the problematization or conceptualising dementia as a disability, and include reference to person centred care (Kitwood, 1997) and relate to people with dementia articulating their own voices (Goldsmith,1996). Although we have seen that our Western conceptualisation has been shaped by a discourse without any specific or direct reference to religious or spiritual belief, these authors might suggest there lies a potential philosophical/spiritual dimension to our *Archive*, underpinned by Western society's Judaeo-Christian beliefs deep within the discourse. Here one may even consider the conceptual frame I have given that their discourse supports 'Dementia as a disability' might also be referred to as 'Dementia as a consequence of spiritual, cultural or value based ideological practice' and could then equally be linked to the humanistic principles echoed in the classical work of Rothschild (1937). This then also suggests a much wider argument that the six conceptualisations found through the course of this study are not fixed. Rather these conceptualisations are dynamic and that other writers/ authors may also

choose to use other alternative labels rather than the ones I have selected to describe them. This then also follows the post-structuralist traditions of this work as being therefore ‘one of many truths’.

This leads however to the important consideration that there are no examples in our *Archive* for example examining divinity, the role of the church, or whether gods, spirits, demons, etc. and their application to problematizing dementia appear. This is a noteworthy point given our early discussions about the links between Western society and Judaeo-Christian beliefs. One reason for this may be from a limitation in its methods. Documents in this area are not readily available and would require more specialist knowledge and time than the limits of this study might allow. However a clear inclusion and exclusion criteria was adopted to the documents collected. Here a clear preference to formalised written text was adopted, and here, reflexivity might suggest a sub-conscious preference or bias to the archiving of medico-scientific texts (this concern in discussed in greater detail in section 4.7 Reflexivity). In reflection, our document exclusion and any additionally associated bias, whether conscious or unconscious, prevented access to a concept that could be better revealed through other forms of discourse. Our methods chapter did make reference to ‘artefacts’ and here the gap lies. Western discourse, particularly historical discourse on spiritual ideas and practices, may be better discovered then in a different type of document than reviewed in this study. It is for these reasons that a final point to make in this discussion is a clear recognition of the possibility for other ways of understanding or speaking about dementia and of the dynamic nature of its problematization that may also lead to the use of other labels which may come and go at different times.

Chapter 7: Conclusion

This study has provided an alternative to the traditional 'total' histories of dementia (Albert, 2005; Beach, 1987; Berchtold and Cotman, 1998; Berrios, 1987, 1995, 2010; Blumer, 1907; Boller, 2008; Boller and Forbes, 1998; Brannon, 1994; Casanova *et al.,* 1998; Cipriani *et al.,* 2011; Desmond, 1996; Förstl, 2000, 2005; Gottfies, 1991; Halpert, 1983; Hodges, 2006; Jellinger, 2006; Kassel, 1965; Lefroy, 2000; Loeb, 1995; Lucci, 1998; Maurer, 2006; Maurer and Hodges, 2006; Möller and Graeber, 1998; Neel and Ostenfeld, 1946; Porter, 1995; Roman, 1999, 2003; Schwartz, 1992). It used a method for doing historical analysis that looked at systems of thought to describe the transformations found within a range of dementia discourse's in Western society that have led to its changing problematization.

This study's intention was not to trace the origins of dementia discourse, as would be the case in traditional histories, but rather to explore its conditions of possibility. This furthers the ideas and work of other writers (Ballenger, 2000, 2006; Berrios, 1990; Burchynsky, 1998; Davis, 2004; Fox, 1999; George *et al.,* 2011; Harding and Palfrey, 1997; Kurz, 2000; McKhann, 2011; Whitehouse, 2000). This is done through not only tracing the ideas and development of dementia through a socio-historical discourse, but by also following post-structuralist methodological traditions and considering notions of dominant and suppressed discourse, power, knowledge and truth. Portrayed in the *Dementia Archive,* possible rules that define the limits of what can and cannot be said about dementia are found.

The study moves beyond traditional histories of dementia as found in the literature review which noted a totalizing analysis of the formation and development of dementia knowledge. Instead a socio-historical analysis, based on a post-structuralist approach (including a Foucauldian archaeology and genealogy), is given to present a general socio-history of dementia. Traditional histories focus on scientific discoveries and innovation (Boller, 2008; Bond, 1992;

Förstl, 2000; Hodges, 2006; Jellinger, 2006; Lucci, 1998; Maurer, 2006; Pollen, 2000; Tanzi, 2013), creating a system of teleological thought based on sedimentation and accumulation. This study however concerned itself with understanding the conditions in which dementia came to be problematized, building on the work of those writers that sought to unpick socio-historical, cultural or philosophical constructions (Ballenger, 2006; Davies, 2004; Dillman, 2000; Harding and Palfrey, 1997; Whitehouse, *et al.,* 2000). This study also considered how changes in the problematization of dementia became the object of analysis. In a clear departure from any attempt to reveal comparative generalisations and produce a totalising discourse, the study instead highlighted the diversity of statements and analysed, in the words of Foucault;

> "The domain of existence and functioning of a discursive practice… to uncover... the particular level in which history can give place to definite types of discourse which have their own type of historicity" (Foucault, 1977:138).

Traditional dementia histories also seeks to describe a clear succession of events, based largely on periodization that have led to the evolution of dementia (Berrios, 1987, 1995; Boller, 2008; Brannon, 1994; Hodges, 2006; Holstein, 1997). Importantly this assumes a singular temporal event of thought or series of temporal relations appearing in linearity. The study departs from this way of thinking, considering instead differing forms of knowledge/power that affect discourse –swapping ideas of linearity and periodization with ideas of discontinuities, ruptures and emerging discourse, leading to its eventual problematization.

Our study also took on a unique genealogical approach that again demonstrated clear departure from traditional histories of dementia that focus on the origin of dementia (Amaducci *et al.,* 1986; Blumer, 1907; Boling and Sommers, 1988). This genealogy of dementia has instead attempted to reveal the disparity that may lie behind any assumed origin of dementia. Understanding the origins of dementia are replaced with explanatory constructs of the descent and emergence for systems of thought and possibility. Traditional histories are pushed aside because they present the history of dementia as either a culmination of periodic

events or as scientific progress. This echoes the concerns of Ballenger *et al.,* (1999), Davis (2004) and Whitehouse (2000). This study rather has sought to understand the struggles between subjugation, dominance, and power/ knowledge, which have led to its problematization in Western society.

7.1 Study overview

This study has explored a short socio-history, archaeology and genealogy of dementia, critically analysing dementia in Western society. It makes note of what it is to be a kind of person with dementia and the kind of professional groups that are created to support care practices. The study departs from traditional histories of dementia that have focused on scientific advances and the people that made these discoveries. It has instead considered the knowledge, truth and power, deep within an evolving dementia discourse that has comprised 500 documents over 4,000 years, the *Archive*. It analysis is based on Foucauldian principles, and draws upon an archaeology and genealogy of the construction of dementia. More specifically, six conceptualisations or problematization of dementia were found. Conceptualisations are found not to be linear nor based on any specific periodization. As such there is no clear movement between periods of psychiatry and medicine that neatly divide the history of AD, as have been suggested by other writers in this area (such as Dillman (1990) who argued for three periods of (i) Kraeplinian psychiatry and neuropathological research, ii) Neuropharmacology and attempts to develop drug treatment for AD, and iii) Molecular genetics and DNA). Nor can it move simply back and forth between social, psychosocial and biological concepts as suggested by Whitehouse (2000). Instead, this study provides evidence of conceptual interplay of problematizations that support a range of conceptualisations to operate interchangeably, but still dependent on systems of thought that weaving between dominance and suppression. This supports the Foucauldian principles that framed a potential hypothesis of there being ‘many truths’ about dementia, rather than just one truth that traditional histories may give way to.

Six clear conceptualisations have been identified in this study, and are shown importantly to be linked to a social apparatus that permits only at certain times, or to certain people, any given discourse to be accepted. Crucially this allows only given parts to be seen or to remain dominant at any point in time but the dominance is still subject to fluidity and can be easily replaced with suppression. The six conceptualisations act dynamically and come and go at different times. The rules that allow such knowledge/truth transformation to take place are however less clear but may be linked to a power relationships between professional groupings; emerging humanistic discourse (Brooker, 2007; Kitwood, 1990,1997; Kitwood and Bredin, 1992; Love and Pinkowitz, 2013); both a political and a socio-economic drive to seek a dementia cure (Centre for Economics and Business Research, 2014; Cutler, 1986; DH, 2009, 2012, 2014; Dementia Action Alliance, 2010; Luengo-Fernandez *et al.,* 2010; WHO, 2012); the role of gene therapy and a desire to find a genetic link (Bertram and Tanzi, 2008; Karch, *et al.,* 2014; Periack-Vance *et al.,* 1991; Pollen, 1996; Tanzi and Bertram, 2005; Tanzi and Parson, 2000; Tobon *et al.,* 1998); the role of dementia pressure groups (Fox, 1989); the empowerment and giving voice to users of services (Boyle, 2014; Davis, 1989; Froggatt, 1988; Goldsmith, 1996; Proctor, 2001); the market 'value' of people with dementia as consumers of services (Alzheimer's Society, 2013, 2014; Bartlett and O'Connor, 2007; Gilliard *et al.,* 2005; Shih-Yin and Lewis, 2015; Thomas and Milligan, 2015); technological information sharing and hyper-cognitive societies (Brittain *et al.,* 2010); the strong associations between ageing, frailty, disability, and terminal illness placed firmly alongside practical concerns on inevitability, increasing dialogues of death and dying and the palliative care movement (Hendriks *et al.,* 2014; Mitchell *et al.,* 2009; Pinzon *et al.,* 2013; Sampson *et al.,* 2009; Simard, 2013; Thomas, 2010; Volicer, 1986; Volicer *et al.,* 1986; WHO, 2004; Wolf-Klein *et al.,* 2007); and, finally a belief system where compassion is more highly valued as a feature of the developed world/societies then economic prowess or warfare (Blackman *et al.,* 2003; Davis *et al.,* 2009; Employers for Carers, 2014; Gillard *et al.,* 2005; National Audit Office, 2007).

It is these potential rules that are in operation. They weave in and out of the social apparatus, as systems of thought and knowledge reflecting the ways in which we can speak of and about dementia. To rely on a single conceptualisation would therefore always be erroneous.

The 'will to know' about dementia then is based on an understanding of the differing yet interplaying concepts that society permits to show at any given time. Depending on the prevailing discourse, at any given time, a certain type of knowledge of dementia will be supported in curricula and guide dementia care, management, and ongoing research. To understand how dementia therefore is conceptualised in Western society is to understand also its socio-history, its archaeology and its genealogy.

7.2 How is dementia conceptualised in Western society?

Conceptualising dementia relates to the abstract underpinnings of the related discourse. In this sense, dementia cannot exist alone unconnected to other ideas or topics. It exists also as a concept within a social apparatus of thought that includes other much wider themes, such as disability, ageing, mental health, death and dying. This social apparatus, comprising of knowledge, truth and power, provides us with an organised way of thinking about dementia and thus creates a lens by which it then becomes problematized.

Both published seminal and current work have been used to develop an *Archive* of thought and problematization of dementia. It has been used here to understand the knowledge, truth and power associated with the concept of dementia giving rise to what is known, unknown, ruptures, discontinuities, inconsistencies and overlaps. Nurses, educationalists and researchers should understand the nature of conceptualisation in dementia and need to be prepared to question dominant discourse and look for possible alternatives, other truths in existence 'out there', other ways of seeing dementia. The conceptualisation of dementia therefore needs careful review and needs to incorporate six alternative albeit inter-connected concepts:

1) Dementia and Ageing.
2) Dementia and Mental disorder.
3) Dementia as Bio-medicine.
4) Dementia and Neurocognitive decline.
5) Dementia and Disability, including person centred practices.
6) Dementia and Terminal Illness.

In understanding a series of alternative conceptualisations, which do not follow an obvious 'scientific progression' or teleological development of scientific discovery as one may first think, dementia care, education and research can develop. A basic conceptual model needs to understand that seminal works may still have important consequences as well as new and emerging ideas. Seminal and current works can and should be used as a guidance to help education and research to identify not only the gaps in teaching and learning outcomes but also, and more importantly, areas of potential conceptual bias. It is important for nurse educators and the dementia researcher to reflect also on their own understanding of their concept of dementia. To what degree does their conceptualisation represent dominant discourse? Through what lens is dementia viewed by the educator/ researcher and how does this then reflect the education of students or research? To which subject or field of practice is dementia education more strongly situated? Who are the lecturers/educators who take on the role of dementia educators?

What we do note is that the concept of dementia is not one-dimensional. We cannot say dementia is this or it is that. The concept of dementia is in contemporary Western society multi-faceted. To say it is exclusively viewed from a neuro-psychiatric conceptualisation would be wrong, although this is how, on the surface it may first have appeared. This study concludes that the dominant perspective at present is to problematize dementia as a neurological condition leading to a terminal illness. Such a view reduces the dominance of psychiatry. This needs to be recognised through nurse education. How far this previously subjugated, but now dominant conceptualisation, would continue is open to debate. Our study certainly shows this will, in due course, be subject to change,

particularly as genetics and modifiable risks gather attention. However, our study also shows that it will never truly disappear for good.

Understanding the changing conceptualisations in dementia has not only demonstrated new areas of thinking but also the emergence of new types of professionals. The effect of this for nursing should equally not be underestimated. Dementia will continue, in Western society, to be a condition requiring nursing support but this being the sole province of mental health nurses is clearly now being put into question. Admiral Nurses, one of the main dementia nurse advanced specialists in the UK once only recruited mental health nurses. However over the last two years they have also recruited adult nurses and learning disability nurses (80% mental health, 20% adult/learning disability) (personal communication with Dementia UK). Although the focus appears still to be with mental health nurses, there are clear signs of challenges to this 'traditional' professional.

The ultimate effect of this then is to not only ensure dementia education is spread across all fields of nursing practice, but also that differing ways of seeing dementia are presented. This, together with the opportunity to engage in learning practices that helps the student nurse to locate dementia within particular conceptual frameworks, would then also help them to understand how such constructs are contingent on the assumptions made by society and are thus open to change, to be dominant or to be subjugated, and thus the need to question dementia care from the 'outside'. Currently the majority of dementia teaching rests largely in mental health nursing curricula, but, given our conceptual predictions, it is likely that this may soon be overtaken by a greater focus in adult nursing content given the growing conceptual ideas and problematization on long term health and terminal illness. It will be interesting to see if this supports a new type of dementia professional in the future – and if so showing the powerful effect discourse may have in creating new kinds of both people and professionals alike.

7.4 Limitations and areas for further research

The completion of this study was not without its limitations. First, the *Archive* identified a large array of documents. The first concern was document access, particularly as many were neither available in print nor held in the local University Libraries. It was useful therefore to have access to the British Library in London as a research student, and in particular having access to the rare books section. However it was surprising that still a number of texts could still not be found. In addition, the phenomena of dementia spanning a range of populations, reaching much further than the English language alone would support, became an important consideration. The inclusion of some of these texts was important in the *Archive* (an important ethical decision so as not to limit work to only the English speaking Western societies), although the ability to then analyse the document would then depend on text translations. Although this was discussed under the methodology section in this study, it still needs to be re-examined here as a limitation as not all documents were translated. In this sense this work is open to be critiqued as a clearly 'Anglicised' version of the conceptualisation of dementia in Western societies.

A second limitation was the breadth of documents that began to fill the *Archive*. Having started the study with no previous knowledge of how long or short this may be, its length was a surprise. A limitation of this study was the practical time it would then take to examine each document in turn, arguably beyond the scope of a much shorter professional doctorate thesis, which was set at a practical 500. As already discussed any additional documents were reviewed to see if they led to a theme not already discussed or whether a relative satiation of discourse had already been met. Examples of documents where this was considered can be seen in appendix 4. All these documents were important but left out as they did not add any different ideas to those already presented (in terms of the problematization of dementia) and the nominal 500 documents had already been met.

A third limitation in accessing which documents were to be included in the *Archive* and then the meaning that I, as the researcher, would give to the text. This is

discussed in greater detail in the methodology chapter. Although this concern focuses on my own understanding of any personal constructs I have that may affect the way I judge either document or text, it also considers the choice I made in document type. The methodology section in this study described a range of 'documents' that could be held open 'to the gaze' and justified what I had selected. However, the choice of document used would give clear preference to certain ways to see or speak of dementia. This is important because ways of seeing dementia may not be limited solely to the printed word. This is interesting for as we note above there is little reference in our *Archive* in seeing dementia as a spiritual conceptualisation. This should not be because dementia is not conceptualised as such in Western society but rather it is to be viewed as a consequence, and thus limitation, of the document type chosen to be included in the *Archive*.

7.5 Original contribution made to the field of study

This study enhances the existing literature in a number of ways. This is because the published literature focuses mainly on Alzheimer's disease, with some limited exceptions. Whilst the history of Alzheimer's disease is of clear historical interest (Fox *et al.,* 1999; Jellinger, 2006; Lacey, 1999; Lefroy, 2000; Maurer, 2006; Maurer and Hoyer, 2006; Muller and Graeber, 1998; Ramirez-Bermudez, 2012; Shua-Haim, 1998; Vannoy and Greene, 1989), other forms of dementia have need consideration too. These have been studied but at a notably much lesser extent than Alzheimer's disease, but have included subcortical dementia (Albert, 2005; Förstl, 2005), vascular dementia (Engelhardt and Grinberg, 2015; Förstl, 2005; McKay and Counts, 2017; Román, 1999, 2003), frontotemporal dementia (Förstl, 2005; Ren *et al.,* 2012; Spatt, 2003) and dementia with Lewy bodies (Ballard, 2004; Buracchio *et al.,* 2005; Jellinger, 2018; Mueller, *et al.,* 2017). In addition, some historicising on dementia as an overall disease has also taken place (Boller and Forbes, 1998; Gottfries, 1991; Papavramidou, 2018) as well as clear attempts to examine conceptual distinctions between Alzheimer's disease and senile dementia (Boling and Sommers, 1988; Hanson, 1991; Hilton, 2015;

Holstein, 1997; Kotsovsky, 1929; Ohry and Buda, 2015; Reisberg, Schwartz and Stark, 1992). Despite these in-roads into dementia history, the histories still continue to order dementia into precise periods of time, continuing to present transformation in thought and knowledge that lead to a history that is both reductive and totalising.

Some writings however take a different approach, critically reviewing the established 'facts' of dementia through the understanding of either cultural history or the politics of scientific progress. Tracing not only neuro-pathological developments but also the social and political role controversies that abound throughout its history, writers such as Ballenger (2006a, 2006b), Berrios (1987, 1995, 2010), Davis (2004); Gubrium (1986), Locke (2013), and Whitehouse (2000) trace the interactions within these developments to question our current ideas about dementia, warning about the over oversimplification of its history. This was important understanding when developing this study.

Choosing then to depart from historical teleological assumptions that changing constructs of dementia are reflective purely of increasing verisimilitude, as can be found in many of the authors above, and by then also drawing on the work of other writers (see Ballenger, 2006a, 2006b; Berrios, 1987, 1995, 2010; Davis, 2004; Gubrium, 1986; Locke, 2013; Whitehouse, 2000, who discuss this concern) to unpick the cultural, political and social controversies that surround its history. Rather than focusing purely on questions of epistemic accuracy a critical focus on changing forms of problematization is instead introduced. Here then we move the debate and our understanding of the history of dementia to instead critically analyse the way dementia is constituted as an object within different discourses of knowledge to examine its problematization and what it is to be a kind of person with dementia.

Further to this then is also a need to take these concerns to a new conceptual level whereby such findings are not only discovered but are also conceptually defined. This relates to how we could choose to understand any of the theoretical debates that come to surround the positioning of dementia in Western society, its problematization, and what the effect of this might be. This is done by analysing

the different discourses of knowledge that have come to surround dementia and in particular to examine the qualities that have come to underpin its problematization and the systems of knowledge or social apparatus within which dementia is constituted.

First it has introduced the idea of an *Archive* of dementia discourse, documenting the rise of how and why this disease became to be spoken of and traces this across a four thousand year history. This *Archive* portrays when dementia became to be recognised as a disease as well as what it was thought to be before its medicalisation. Here, the *Archive*, its archaeology, includes 500 documents ranging from historical scholarly texts, diagnostic classifications, assessment tools, journal publications and other articles.

Secondly this study takes results from the *Archive* to create a genealogy of discourse that gives a deeper understanding of the problematization of dementia and its changing conceptualisation. We find it divided into six differing ways of conceptualising dementia in the socio-history of dementia thought and its problematization. This is represented by conceptualising dementia as a natural consequence of ageing, as a mental disorder, a neurological disorder, a cognitive impairment, a disability and finally as a terminal condition. This builds on the previous work of Downs *et al*., (2006) who described four possible ways or models of representing dementia, including as a neuro-psychiatric condition, neurological condition, normal ageing, and dementia from a person-centred perspective. This study not only adds to this seminal piece of work by presenting other ways of seeing dementia, but also attempts to provide a socio-history and explanation for why and how these ideas took form in the first place, expanding then also the important work of Ballenger (2006a, 2006b), Berrios (1987, 1995, 2010), Gubrium (1986), Locke (2013), and Whitehouse (2000).

7.6 Summary

This study is concluded with the argument that dementia is moving away from a dominant mode of conceptualising dementia as a neuro-psychiatric condition to

instead seeing it as a disability and a terminal illness. It predicts that in time ways of seeing dementia in terms of a mental disorder supported chiefly by old age psychiatry and mental health nurses will in fact become themselves subjugated points of reference. Moves to create dementia friendly environments and to support disabling aspects of the condition will allow social models to dominate over medical models of care practices. However as our six conceptual framework model shows, limits to the social model will no doubt also begin to show leaving a new interplay between neuro-cognitive conceptualisations. This will be particularly important for people in the early and middle stages of dementia, through to then terminal illness conceptualisations for people with advanced dementia or nearing end of life. As this take effect, it is likely to cause a potential resurgence of some aspects of the medical model – a clear example of the trend we have seen in our socio-history where there is no linear progression between conceptualisation. Ironically for nurse education, the reign of the mental health nurse and the old age psychiatrist as the key professionals involved may no longer be the only case – their legitimization being based only on explanatory constructs in operation at a particular temporal moment in time.

Nurse education, dementia practice, dementia studies and dementia research must accept that the way we conceptualise dementia has a direct effect on our practices in all these areas. What we come to see as legitimate is actually only a feature of the prevailing discourse at the time, drawn upon by the social apparatus and systems of knowledge that governs professional practices. These practices operate then to both include and preclude what we come to view as knowledge and truth in dementia care. This exerts a controlling effect on how these services become shaped, how nursing curriculums are designed, and research studies, including ethics committees, intellectual paradigms and methodological approaches are then focused. This study has highlighted six examples of conceptualisations. It has also argued that any non-legitimised or dominant concept never truly disappears but instead lays in wait for the right type of social conditions or apparatus (system of thought and knowledge) that permit its re-emergence.

7.6.1 Study recommendations

This study gives a series of recommendations. First, dementia teaching should remain a core feature of nurse education for all fields of practice. However how the individual HEIs, as well as professional regulatory bodies direct the course content of dementia education, ought then to be carefully considered. Any direction towards a particular way of seeing dementia, such as suggesting an increased content for mental health nurse students and lesser content for adult nurse students should be recognised as having potential for being neuro-psychiatric dominant. The HEI must recognise that professional bodies may operate within the constraints of seeing dementia from a limited range of perspectives. This creates a need to carefully consider other explanatory constructs to locate dementia that could be employed within the teaching and learning curriculum content. In this sense there is potential that the range of differing conceptualisations as shown in this study could serve as a check point for course/programme designers in ensuring our future nurses can work well, and also question the conceptualisations we find in our socio-history, knowing how our past helps us make sense of the present.

Secondly, where a particular construct or problematization is given greater weight by a professional regulatory body, then the curriculum must respond by also supporting discussion with the students into how this way of seeing came about, its socio-history of thought, and the knowledge/power constraints and systems of thought involved. Students must be guided to explore and to challenge this as an essential requirement of higher education, although the depth of this analysis would depend on the academic level being studied at.

Thirdly, for those researching dementia care and its practice, careful self-reflection by the researcher should take place, discovering their own personal conceptual reference for dementia. No matter how objective the researcher may aim to be, he or she will be guided by their own inner reflectivity on how they choose to see dementia. This then becomes an ethical discussion and a limitation

to the research which ought to be made clear and transparent. Without such transparency a system of thought is likely to be created that may lead to a continuous and self-reinforcing intellectual paradigm. This would cause other forms of understanding of what it is to be a person with dementia to become destabilised and subjugated. Here the views of any given set of researchers in the field become dominant and may affect in turn the research and practice of others. A way of researching dementia that becomes dominant is then created. Researchers must think carefully how they choose to think about dementia and how this then may affect not only their methodological approach, but also the opportunities their research creates in supporting, constraining, limiting or challenging other forms of dementia discourse.

Fourthly, a potential output of this study is the development of a 'Six Conceptual Model' approach to understanding dementia. This could be used to help guide and inform practitioners, dementia curricula, professional regulatory standards, national guidance papers and researchers of domains of problematization and support practice development to question from the outside.

Fifthly, a Dementia *Archive* has been created as one of the original contributions to the field of knowledge in this area of dementia. One could suggest, despite the limitations presented by the study, it presents a useful starting point for developing a clear *Archive* of dementia discourse – a resource potentially available to support dementia studies both nationally and nationally (teaching/learning and research). Further development of the *Archive*, including a form of Delphi review with a range of HEIs, service providers and service users could be undertaken to produce a more polished and arguably less biased presentation. Once agreed by some form of international consensus, electronic examples of the documents contained could be procured and housed in what would then become the first international *Dementia Archive* on Western thought, housed within the DMU Library but accessed by any subscribing institution interested in dementia studies.

Finally, this study focused on Western society. To compare and contrast its findings with the discursive practices appearing in minority communities co-

existing in Western society, offering a whole new range of inter-cultural beliefs might prove an interesting addition.

7.6.2 Concluding remarks

We finally conclude this study arguing the way we conceptualise dementia in Western society will shape how we choose to educate the professionals we task to care for them, affect our research agendas, and determine any given dementia pedagogy, influencing both curricula, standards and methods. Importantly, our socio-history and genealogy has allowed us to question dementia as a mental disorder or neuro-psychiatric condition, a view reported to be in evidence in contemporary society, and instead evidenced other ways of problematizing dementia. This construct however is contingent on what Western society, through its systems of thought and knowledge will permit and challenge. This leaves us, as a society, with a task or call to arms - what we now decide or choose to do about it. Reflecting on our initial Foucauldian principles that have guided the intellectual paradigm shaping this study, this choice would no doubt be a clear measure of the true operation of knowledge/power and 'truth' in Western society for dementia.

References

Aarsland, D., Bronnick, K., Larsen, J.P., Tysnes, O.B., and Alves, G. (2009) Cognitive impairment in incident, untreated Parkinson's disease. The Norwegian ParkWest study. *Neurology*, 72(13):1121-1126.

Abrams, P. (1982) *Historical sociology*. Bath: Pitman Press.

Abudy, A., Juven-Wetzler, A., and Zohar, J. (2014) The different faces of Creutzfeldt-Jacob disease CJD in psychiatry. *General Hospital Psychiatry*, 36(3):245-248.

Ackerknecht, E. and Vallois, H. (1956) *Franz Joseph Gall, Inventor of Phrenology and His Collection*. Madison: Wisconsin Medical School.

Adams, T. (2008) *Dementia care nursing. Promoting well-being in people with dementia and their families*. Hampshire: Palgrave Macmillan.

Adams, T. (2010) The applicability of a recovery approach to nursing people with dementia. *International Journal of Nursing Studies,* 47:626-634.

Albert, M. (2005) Subcortical dementia: historical review and personal view. *Neurocase,* 11(4):243-245.

Albert, M. and Cohen, C. (1992) The test for severe impairment: an instrument for the assessment of patients with severe cognitive dysfunction. *Journal of the American Geriatrics Society,* 40:449-453.

Albert, M.L., Feldman, R.G., and Willis, A.L. (1974) The 'subcortical dementia' of progressive supranuclear palsy. *Journal of Neurology, Neurosurgery and Psychiatry*, 37(2):121-130.

Alexander, F.G. and Selesnick, S.T. (1966) *The history of psychiatry*. New York: Harper and Row.

Alexopoulos, P. and Kurz, A. (2015) The new conceptualization of Alzheimer's disease under the microscope of influential definitions of disease. *Psychopathology,* 48(6):359-367.

All Parliamentary Group on Dementia (2009) *Prepared to care. Challenging the dementia skills gap.* London: APGD.

All Parliamentary Group on Dementia (2012) *Unlocking diagnosis.* London: Alzheimer's Society.

All Parliamentary Group on Dementia (2013) *Dementia does not discriminate.* London: Alzheimer's Society.

All Parliamentary Group on Dementia (2014) *Building on the national dementia strategy: change, progress and priorities*. London: Alzheimer's Society.

Allan, K. (2001) *Communication and consultation – exploring ways for staff to involve people with dementia in developing services.* Bristol: Joseph Rowntree Foundation/ The Policy Press.

Allport, G.W. (1942) *The use of personal documents in psychological science.* New York: Social Science Research Council.

Alushi, L., Hammond, J.A. and Wood, J.H. (2015) Evaluation of dementia education programmes for pre-registration healthcare students: a review of the literature. *Nurse Education Today,* 35(9):992-998.

Alzheimer, A. (1894) Die arteriosklerotische atrophie des gehirns. *Neurologisches Zentralblatt*, 13:765-768.

Alzheimer, A. (1898) Neuere Arbeiten über die Dementia senilis und die auf atheromatöser Gefässerkrankung basierenden Gehirnkrankheiten. *Monatsschrift für Psychiatrie und Neurologie*, 3:101-115.

Alzheimer, A. (1899) Beitrag zur pathologischen Anatomie der Seelenströrungen des greisenalters. *Neurol Zentralblatt*, 18:95-96.

Alzheimer, A. (1902) Die seelenströrungen auf arteriosklerotischer grundlage. *Allgemeine Zeitschrift fur Psychiatrie und psychisch-gerichtliche Medicine*, 59:695-711.

Alzheimer, A. (1907) Über eine eigenartige Erkrankung der Hirnrinde. *Allgemeine Zeitschrift für Psychiatrie*, 64:146-148.

Alzheimer, A. (1911) Uber eigenartige Krankheitsfalle des spateren Alters. *Neurol. Psychiat*, 4:356-385.

Alzheimer's Association (2009) *Alzheimer's disease facts and figures.* Chicago: Alzheimer's Association.

Alzheimer's Disease and Related Disorders Association, ADRDA (1987) *National Program to Conquer Alzheimer's Disease*. Chicago IL: ADRDA.

Alzheimer's Society (2005) *Policy position: demography.* Available from: http://www.alzheimers.org.uk/News_and_Campaigns/Policy_Watch/demography.htm [accessed 12.11.12].

Alzheimer's Society (2006) *Facts about dementia.* Available from: http://www.alzheimers.org.uk/Facts_about_dementia/What_is_dementia/Index.htm [accessed 12.11.12].

Alzheimer's Society (2007) *Dementia UK: A report to the Alzheimer's society on the prevalence and economic cost of dementia in the UK produced by King's College London and the London School of Economics.* London: Alzheimer's Society.

Alzheimer's Society (2009) *Counting the Cost: caring for people with dementia on hospital wards.* London: Alzheimer's Society.

Alzheimer's Society (2013a) *Building dementia-friendly communities: a priority for everyone*. London: Alzheimer's Society.

Alzheimer's Society (2013b) *The hidden voice of loneliness*. London: Alzheimer's Society.

Alzheimer's Society (2014a) *Dementia 2014: Opportunity for Change*. London: Alzheimer's Society.

Alzheimer's Society (2014b) *Dementia UK. Second edition.* London: Alzheimer's Society.

Alzheimer's Society (2014c) *How to help people with dementia: a guide for customer-facing staff*. London: Alzheimer's Society.

Amaducci, L.A., Rocca, W.A. and Schoenberg, B.S. (1986) Origin of the distinction between Alzheimer's disease and senile dementia: how history can classify nosology. *Neurology,* 36(11):1497-1499.

American Psychiatric Association (1952) *Diagnostic and statistical manual of mental disorders (DSM-I).* Washington DC: APA

American Psychiatric Association (1968) *Diagnostic and statistical manual of mental disorders, DSM-II.* (2nd ed.) Washington DC: APA.

American Psychiatric Association (1980) *Diagnostic and statistical manual of mental disorders, DSM-III.* (3rd ed.) Washington DC: APA.

American Psychiatric Association (1987) *Diagnostic and statistical manual of mental disorders, DSM-III-R.* (3rd ed. revised) Washington DC: APA.

American Psychiatric Association (1994) *Diagnostic and statistical manual of mental disorders, DSM-IV.* (4th ed.) Washington DC: APA.

American Psychiatric Association (2013) *Diagnostic and statistical manual of mental disorders, DSM-5.* (5th ed.) Washington DC: APA.

Ang, L. (1985) *Watching Dallas.* London: Methuen.

Ariga, H. (2015) Common mechanisms of onset of cancer and neurodegenerative diseases. *Biological and Pharmaceutical Bulletin*, 6:795-808.

Armstrong, D. (1982) Pathological life and death: Medical spatialisation and geriatrics. *Social Science and Medicine,* 15A:253-257.

Arnold, J.H. (2000) *History. A short introduction.* Oxford: Oxford University Press.

Ashton, S. (2016) Dementia awareness. In: Smith, G. (ed.), Dementia care. A practical approach. Boca Raton, London, New York: CRC Press.

Attems, J. and Jellinger, A.K. (2013) Neuropathology. In: Dening, T. and Thomas, A. (eds.) *Oxford textbook of old age psychiatry.* (2nd ed.) Oxford: Oxford University Press, pp.87-105.

Attridge, D. (1987) Language as history/history as language: Saussure and the romance of etymology. In: Attridge, D., Bennington, G. and Young, R. (eds.) *Post-structuralism and the question of history.* Cambridge: Cambridge University Press, pp.183-211.

Attridge, D., Bennington, G. and Young, R. (1987) *Post-structuralism and the question of history.* Cambridge: Cambridge University Press.

Austin, A.L. (1958) The historical method in nursing. *Nursing Research,* 7(1):4-10

Babcock, H. (1930) An experiment in the measurement of mental deterioration. *Archives of Psychology*, 18:5-105.

Bacon, R. (1966) *De retardation accidentum senectutis*. Hants: Gregg.

Baeck, L. (1958) *Judaism and Christianity.* Philadelphia: The Jewish Publication Society of America.

Baglietto-Vargas, D., Chen, Y., Suh, D., Ager, R.R., Rodriguez-Ortiz, C.J, Medeiros, R., Myczek, K., Green, K.W., Baram, T.Z. and La Ferla, F.M. (2015) Short-term modern life-like stress exacerbates Abeta-pathology and synapse loss in 3xTg-AD mice. *Journal of Neurochemistry,* 134(5):915-926.

Baille, L., Sills, E. and Thomas, N. (2016) Educating a health service workforce about dementia: a qualitative study. *Quality in Ageing and Older Adults,* 17(2): 119-130.

Ball, B. and Chambard, E. (1881) Démence apoplectique. In: Dechambre, A. and Lereboullet, L. (eds.) *Dictionaire Encyclopedique des sciences medicales.* Paris: Masson.

Ballenger, J.F. (2000) Beyond the characteristic plaques and tangles: mid-twentieth century U.S. psychiatry and the fight against senility. In: Whitehouse, P.J., Maurer, K. and Ballenger, J.F. (eds.) *Concepts of Alzheimer Disease. Biological, Clinical and Cultural Perspectives.* London: The John Hopkins University Press, pp.83-103.

Ballenger, J.F. (2006a) Progress in the history of Alzheimer's disease: the importance of context. *Journal of Alzheimer's Disease,* 9(3 Suppl.):5-13.

Ballenger, J.F. (2006b) *Self, senility, and Alzheimer's disease in modern America – a history.* Baltimore: The John Hopkins University Press.

Ballenger, J.F. (2017) Framing confusion: dementia, society, and history. *AMA Journal of Ethics,* 19(7):713-719.

Ballenger, J.F., Nelson, J.L. and Whitehouse, P.J. (1999) Beyond "progress" in the history of Alzheimer disease. *Alzheimer Disease and Associated Disorders,* 13(3):130-131.

Barfus, R.T., Dean, R.L., Beer, B. and Lippa, A.S. (1982) The cholinergic hypostudy of geriatric memory dysfunction. *Science,* 217:408-417.

Barnes, C. (2012) Understanding the social model of disability: past, present and future. In: Watson, N., Roulstone, A. and Thomas, C. (eds.) *Routledge Handbook of Disability Studies*. London: Routledge, pp. 12-29.

Barnes, D.E., Kaup, A., Kirby, K.A., Byers, A.L., Diaz-Arrastia, R. and Yaffe, K. (2014) Traumatic brain injury and risk of dementia in older veterans. *Neurology*, 83(4):312-319.

Barrett, A.M. (1911) Degeneration of intracellular neurofibrils with military gliosis in psychosis of the senile period. *American Journal of Insanity,* 57:503.

Barrett, A.M. (1913) A case of Alzheimer's disease with unusual neurological disturbances. *The Journal of Nervous and Mental Disease,* 40:361-374.

Barrough, P. (1583) Of Memory Lost. In: *The methode of phisicke, conteyning the causes, signes, and cures of inward diseases in man's body from the head to the foote*. London: Thomas Vautroullier dwelling in the Blackefriars by Ludgate.

Barthes, R. (1981[1967]) The Discourse of History (trans. Bann, S. 1981). In: Shaffer, E.S. (ed.) *Comparative criticism: a yearbook 3*. Cambridge: Cambridge University Press.

Bartlett, R. and O'Connor, D. (2007) From personhood to citizenship: broadening the lens for dementia practice and research. *Journal of Aging Studies,* 21:107-118.

Bastow, S., Dunleavy, P. and Tinkler, J. (2014) *The impact of the social sciences: how academics and their research make a difference.* London: Sage

Beach, T.G. (1987) The history of Alzheimer's disease: three debates. *Journal of the History of Medicine and Allied Sciences,* 42(3):327-349.

Beard, G.M. (1874) *Legal responsibility in old age: based on researches into the relation of age to work.* New York: Russells' American Steam Printing House.

Beattie, A., Daker-White, G., Gilliard, J. and Means, R. (2005) They don't quite fit the way we organise our services – results from a UK field study of marginalised groups and dementia care. *Disability and Society,* 20(1):67-80.

Beer, C., Horner, B., Almeida, O., Almedia, O.P., Scherer, S., Lautenschlager, N.T., Bretland, N., Flett, P., Schaper, F. and Flicker, L. (2009) Current experiences and educational preferences of general practitioners and staff caring for people with dementia living in residential facilities. *BMC Geriatrics,* 9:36.

Beetham, M. (1996) *A magazine of their own: domesticity and desire in the women's magazine 1800-1914.* London: Routledge.

Behuniak, S.M. (2011) *The living dead? The construction of people with Alzheimer's disease as Zombies*. *Ageing and Society,* 31:70-92.

Belle, S.H., Mendelson, A.B., Seaberg, E.C. and Ratcliff, G. (2000) A brief cognitive screening battery for dementia in the community. *Neuroepidemiology,* 19:43-50.

Belsey, C. (2002) *Poststructuralism. A very short introduction.* Oxford: Oxford University Press.

Benedict, R.H., Bakshi, R., Simon, J.H., Priore, R., Miller, C. and Munschauer, F. (2002) Frontal cortex atrophy predicts cognitive impairment in multiple sclerosis. *Journal of Neuro psychiatry and Clinical Neuroscience*, 14(1):44-51.

Benson, D., Frank, R., Davis, J. and Snyder, B.D. (1988) Posterior cortical atrophy. *Archives of Neurology,* 45(7):789-793.

Behhabib, H., Lancôt, K.L., Eryavec, G.M., Li, A. and Herman, N. (2013) Responsiveness of the QUALID to improved neuropsychiatric symptoms in patients with Alzheimer's disease. *Canadian Geriatric Journal,* 16(4):180-185.

Bennington, G. and Young, R. (1987) Introduction: posing the question. In: Attridge, D., Bennington, G. and Young, R. (eds.) *Post-structuralism and the question of history.* Cambridge: Cambridge University Press, pp.1-11.

Berchtold, N.C. and Cotman, C.W. (1998) Evolution in the conceptualisation of dementia and Alzheimer's disease: Greco-Roman period to the 1960s. *Neurobiology of Ageing,* 19(3):173-189.

Beresford, P. (2002) Thinking about 'mental health': towards a social model. *Journal of Mental Health*, 11(6):581-584.

Berg, L. (1985) Does Alzheimer's disease represent an exaggeration of normal ageing? *Archives of Neurology,* 42:1097-1105.

Berg, M. (1996) Practices of reading and writing: the constitutive role of the patient record in medical work. *Sociology of Health and Illness,* 18(4):499-524.

Bert, P. (1864) Expériences et considerations sur la greffe animale. *Journal de L'Anatomie et de la Physiologie,* 1:69-87.

Bertram, L. and Tanzi, R.E. (2008) Thirty years of Alzheimer's disease genetics: systematic meta-analyses herald a new era. *Nature Reviews Neuroscience,* 9:768-778.

Berrios, G. (1996) *The history of mental symptoms: descriptive psychopathology since the nineteenth century.* Cambridge: Cambridge University Press.

Berrios, G. (2010) Dementia: Historical review. In: Ames, D., Burns, A. and O'Brien, J. (eds.) *Dementia.* (4th ed.) London: Hodder Arnold, pp.5-17.

Berrios, G. and Porter, R. (1995) *A history of clinical psychiatry – the origin and history of psychiatric disorders*. London: Athlone.

Berrios, G.E. (1981) *Delirium and confusion during the nineteenth century: a conceptual history*. *British Journal of Psychiatry,* 139:439-449.

Berrios, G.E. (1984) Descriptive psychopathology: conceptual and historical aspects. *Psychological Medicine,* 14:303-313.

Berrios, G.E. (1987) Dementia during the seventeenth and eighteenth centuries: a conceptual history. *Psychological Medicine,* 17(4):829-837.

Berrios, G.E. (1990a) Alzheimer's disease: a conceptual history. *International Journal of Geriatric Psychiatry,* 5:355-365.

Berrios, G.E. (1990b) Memory and the cognitive paradigm of dementia during the 19th century: a conceptual history. In: Murray, R. and Turner, T. (eds.) *Lectures on the History of Psychiatry*. London: Gaskell, pp.194-211.

Berrios, G.E. (1995a) Delirium and Cognate States. In: Berrios, G.E. and Porter, R. (eds.) *A History of Clinical Psychiatry. The origin and history of psychiatric disorders*. London: The Athlone Press, pp. 3-22.

Berrios, G.E. (1995b) Dementia. Clinical section. In: Berrios, G.E. and Porter, R. (eds.) *A History of Clinical Psychiatry. The origin and history of psychiatric disorders*. London: The Athlone Press, pp. 34-51.

Biennow, K., Hampel, H., Weiner, M. and Zetterberg, H. (2010) Cerebrospinal fluid and plasma biomarkers in Alzheimer's disease. *Nature Reviews Neurology,* 6(3):131-144.

Billig, M., Condor, S., Edwards, D. and Radley, A. (1988) *Ideological dilemmas: a social psychology of everyday thinking*. London: Sage.

Binswanger, O. (1893) *Die pathologische histologie der grosshirnrinden-erkrankung bei der Allgemeinen Progressiven Paralyse.* Jena, Germany: Gustav Fischer

Binswanger, O. (1894) Die Abgrenzung der Allgemein progressive Paralyze. *Berl. Klin. Wochenscher*, 31:1103-1105, 1180-1186.

Bird, M. (2000) Psychosocial management of behaviour problems in dementia. In: O'Brien, J., Ames, D. and Burns, A. (eds.) *Dementia*. London: Hodder Arnold, pp. 193-205.

Blackman, T.I.M., Mitchell, L., Burton, E., Jenks, M., Parsons, M., Raman, S. and Williams, K. (2003) The accessibility of public spaces for people with dementia: a new priority for the open city. *Disability and Society,* 18(3):357-371.

Blanchard, S. (1726) *The physical dictionary wherein the terms of anatomy, the names and causes of diseases, chirurgical instruments, and their use, are accurately described.* London: John and Benjamin Sprint.

Blessed, G., Tomlinson, B.E. and Roth, M. (1968) The association between quantitative measures of dementia and senile change in the cerebral grey matter of elderly subjects. *British Journal of Psychiatry*, 114:797-811.

Bleuler, E. (1924) *Textbook of Psychiatry*. (trans. Brill, A.A.). New York: MacMillan.

Blocq, P. and Marienesco, G. (1892) Sur les lesions et la pathogénie de l'épilepsie dite essentielle. *Semaine Medical*, 12:445-446.

Blumer, G. (1907) The history and use of the term dementia. *American journal of Insanity,* 63:337-348.

Blumer, M. (1980) Why don't sociologists make more use of official statistics? *Sociology,* 14(4):505-523.

Board, M., Heaslip, V., Fuggle, K., Gallagher, J. and Wilson, J. (2012) How education can improve care for residents with dementia. *Nursing Older People,* 24(5):29-31.

Boerhaave, H. (1751) *Praelectiones academicae.* In: Von Haller, A. (ed.) Volume 3. Venice.

Boissier de Sauvages, F. (1771) *Nosologia Metodica Morborum Classes.* N Pezzana: Venetiis.

Boling, T.E. and Sommers, K. (1988) Alzheimer's disease. "A 1980's concept for senility"? *Nursing Homes and Senior Citizen Care,* 37(1):24-27.

Boller, F. (2008) History of dementia. In: Boller, F. (ed.), *Handbook of clinical neurology, vol. 89.* London: Elsevier, pp. 3-13.

Boller, F. and Forbes, M.M. (1998) History of dementia and dementia in history: an overview. *Journal of the Neurological Sciences,* 158:125-133.

Bolton, J.S. (1905) Amentia and dementia: A clinic-pathological study. *Journal of Mental Science*, 51:270-336.

Bond, J. (1992) The medicalisation of dementia. *Journal of Ageing Studies,* 6(4):397-403.

Bonfiglio, F. (1908) Di speciali reperti in un caso di probabile sifilide cerebrale. *Rivista Sperimentale di Freniatria,* 34:196-206.

Botwinick, J. and Birren, J.E. (1951) Differential decline in the Wechsler-Bellevue subtests in the senile psychoses. *Journal of Gerontology,* 6:365.

Boyle, G. (2014) Recognising the agency of people with dementia. *Disability and Society,* 29(7):1130-1144.

Braak, H. and Braak, E. (2000) Neuropathological staging of Alzheimer-related changes. *Journal of Neuropathology and Experimental Neurology,* 59:733-748.

Bradley, S., Bellis, A., Guerin, P., Walter, B.K., Wotherspoon, A.J., Cecchin, M. and Paterson, J. (2010) Re-enacted case scenarios for undergraduate healthcare students to illustrate person-centred care in Dementia. *Educational Gerontology,* 36:809-823.

Brandt, A.M. (1985) *No magic bullet: a social history of venereal disease in the united states since 1880*. New York: Oxford University press.

Brandt J, Spencer M, and Folstein, M. (1988) The telephone interview for cognitive status. *Neuropsychiatry, Neuropsychology and Behavioural Neurology,* 1:111-117.

Brannon, W.L. (1994) Alois Alzheimer (1864-1915).II. Dementia before and after Alzheimer: a brief history. *Journal of the South Carolina Medical Association,* 90(9):402-403.

Braudel, F. (1969 [1958]) Histoire et sciences socials: La longue durée. In: Ecrits sur l'histoire. Paris: Flammarion, pp.41-83.

Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology,* 3(2): 77-101.

Brittain, K., Corner, L., Robinson, L. and Bond, J. (2010) Ageing in place and technologies of place: the lived experience of people with dementia in changing social, physical and technological environments. *Sociology of Health and Illness,* 32(2): 272-287.

Brodaty, H. and Moore, C.M. (1997) The clock drawing test for dementia of the Alzheimer's type: a comparison of three scoring methods in a memory disorder clinic. *International Journal of Geriatric Psychiatry,* 12:619-627.

Brodaty, H., Pond, D., Kemp, N.M., Luscombe, G., Harding, L., Berman, K. and Huppert, F.A. (2000) The GPCOG: A new screening test for dementia designed for general practice. *Journal of the American Geriatrics Society,* 50:530-534.

Brody, A.A. and Galvin, J.E. (2013) A review of interprofessional dissemination and education interventions for recognizing and managing dementia. *Gerontology and Geriatrics Education,* 34(3):225-256.

Brooker, D. (2004) What is person-centred care for people with dementia? *Reviews in Clinical Psychology,* 13:215-222.

Brooker, D. (2007) *Person Centred Care*. London: Jessica Kingsley.

Brooker, D. and Latham, I. (2015) Person-centred dementia care: making services better with the VIPS framework. London: Jessica Kingsley.

Brotchie, J. (2003) *Caring for someone with dementia*. London: Age Concern England.

Brown, R.G. and Marsen, C.D. (1988) Subcortical dementia: the neuropsychological evidence. *Neuroscience*, 25:363-387.

Bryan, C.P. (1930) *The Papyrus Ebers.* Herts: The Garden City Press Ltd.

Bryson, N., Holly, M.A. and Moxey, K. (1991) Visual theory: painting and interpretation. Cambridge: Polity Press.

Buchman, A., Boyle, P., Wilson, R., Yuxiao, T. and Bennett, D. (2007) Frailty is associated with incident Alzheimer's disease and cognitive decline in the elderly. *Psychosomatic Medicine*, 69:483-489.

Burchynsky, S. (1998) Problems of dementia: the history of formation of ideas about the nature of Alzheimer's disease. *The Ukrainian Historical and Medical Journal* 1997-1998, (7-8):52-53.

Burke, P. (1992) *Sociology and history.* London: G Allen and Unwin.

Burnett, J. (1984) *The autobiography of the working class.* Brighton: Harvester Press.

Burns, A., Lawlor, B. and Craig, S. (2009) *Assessment scales in old age psychiatry.* (2nd ed.) London: Informa healthcare.

Burns, A.S., Purandare, N. and Craig, S. (2002) *Mental health in older people in practice*. London: Royal Society of Medicine Press Ltd.

Buschke, H. (1973) Selective reminding for analysis of memory and learning. *Journal of Verbal Learning and Verbal Behaviour,* 12:543-550.

Buschke, H., Kuslansky, G., Katz, M., Stewart, W.F., Sliwinski, M.J., Eckholdt, H.M. and Lupton, R.B. (1999) Screening for dementia with the memory impairment screen. *Neurology,* 52(2):231-238.

Butler, R.N. (1980) Senility reconsidered. *Journal of the American Medical Association,* 224(3):259-263.

Butler, R. (2008) *The longevity revolution: the benefits and challenges of living a long life*. New York: Public Affairs.

Butterfield, H. (1931) *The whig interpretation of history.* London: G. Bell and Sons.

Byrnes, C.M. (1913) A clinical and pathological study of a condition occurring in the aged usually attributed to cerebral arteriosclerosis. *Journal of Nervous and Mental Diseases,* 43:489-504.

Camp, C.J. (1998) Memory interventions for normal and pathological older adults. In: Schulz, R., Maddox, G. and Lawton, M.P. (eds.) *Annual review of gerontology and geriatrics, vol. 18, interventions and research with older adults.* New York: Springer.

Canguilhem, G. (1991 [1904]) *The normal and the pathological.* (trans. Fawcett, C.R. 1991). New York: Zone Books.

Carers Trust (2013) *Triangle of care – carers included: a guide to best practice for dementia care*. London: Carers Trust.

Carlino, E., Benedetti, F., Rainero, I., Asteggiano, G., Cappa, G., Tarenzi, L., Vighetti, S. and Pollo, A. (2010) Pain perception and tolerance in patients with frontotemporal dementia. *Pain,* 151(3):783-789.

Carr, E.H. (1961) *What is history?* London: Penguin.

Casanova, M.F., Struble, R.G., Whitehouse, P.J. and Price, D.L. (1998) A historical perspective on the neuropathology of dementia with emphasis on the senile plaque. *Boletin De La Association Médica De Puerto Rico,* 80(11):424-428.

Centre for Economics and Business Research (2014) *Cost of dementia to business.* London: CEBR.

Charcot, J.M. (1867) *Lécons sur les Maladies des Viellards et les Maladies Chroniques*. Paris (trans. by Tuke, W.S., 1881) Clinical lectures on senile and chronic diseases. London: New Sydenham society.

Charcot, J.M. (1881) Clinical lectures on senile and chronic diseases (trans. Tuke, W.S.). London: New Sydenham Society.

Choi, S.H., Kim, Y.H., Hebisch, M., Sliwinski, C., Lee, S., D'Avanzo, C., Chen, H., Hooli, B., Asselin, C., Muffat, J., Klee, J.B., Zhang, C., Wainger, B.J., Peltz, M., Kovacs, D.M., Woolf, C.J., Wagner, S.L., Tanzi, R.E. and Kim, D.Y. (2014) A three-dimensional human neural cell culture model of Alzheimer's disease. *Nature,* 515(7526):274-278.

Christi, T.E. (1975) The methodology of historical research: a brief introduction. *Nursing Research,* 24(3):189-192.

Christian, H.A. (1947) The Principles and Practice of Medicine. (16th ed.) New York: Appelton.

Cipriani, G., Dolciotti, C., Picchi, L. and Bonuccelli, U. (2011) Alzheimer and his disease: a brief history. *Neurological Sciences,* 32:275-279.

Clare, L. and Woods, B. (2001) A role for cognitive rehabilitation in dementia care. *Neuropsychol. Rehabilitation,* 11:193-196.

Clark, M., Gosnell, M. and Witherspoon, D. (1984) A slow death of the mind. *Newsweek*, December, 3:25-28.

Clarke, J.M. (1897) On Huntingtin's chorea. *Brain: A Journal of Neurology*, 1:22-34.

Clarke, P. (2015) The impact market. *Performance Research,* 20(4):112-121

Clouston, T.S. (1898) *Mental Diseases.* (5th ed.) London: Churchill.

Clouston, T.S. (1911) *The Unsoundness of Mind*. New York: Dutton.

Cohen, A.A. (1971) *The myth of the Judaeo-Christian tradition: and other dissenting essays*. New York: Schocken books.

Cohen, G. (1983) Historical views and evolution of concepts. In: Reisberg, B. (ed.), *Alzheimer's Disease: The Standard Reference*. New York: Free Press, pp. 29-33.

Combe, A. (1834) *Observations on mental derangement.* 1972 facsimile reproduction of the first American edition. Delmar NY: Scholars Facsimiles and Reprints.

Conboy, I.M., Conboy, M.J., Wagers, A.J., Girman, E.R., Weissman, I.L. and Rando, T.A. (2005) Rejuvenation of aged progenitor cells by exposure to a young systemic environment. *Nature,* 433(7027):760-764.

Connelly, P.J. and Jamieson, F.E. (1991) Objective assessment of praxis – the OPA diagram – simply testing for dementia. *International Journal of Geriatric Psychiatry,* 6:667-672.

Constantinidis, J., Richard, J. and Tissot, R. (1974) Pick's disease. Histological and clinical correlations, *European Neurology,* 11(4):208-217.

Cook, R.H., Schneck, S.A. and Clark, D.B. (1981) Twins with Alzheimer's disease. *Archives of Neurology*, 38:300-301.

Corder, E., Saunders, A., Strittmatter, W., Schmechel, D., Gaskell, P., Small, G., Roses, A., Haines, J. and Perirak-Vance, M. (1993) Gene dose of apolipoprotein E type 4 alle and the risk of Alzheimer's disease in late onset families. *Science,* 261:921-923.

Cosin, R. (1592) *Conspiracie for pretended reformation: viz. presbyteriall discipline.* London: Barker.

Courbon (D'Amiens) (1912) Intégrité de la mémoire et démence. *Rev. Psychiatr.,* 16:448-455.

Coxon, T. (1988) 'Something sensational'. The sexual diary as a tool for mapping detailed sexual behaviour. *Sociological Review,* 36(2):353-367.

Coyle, J.T., Price, D.L. and Delong, M.R. (1982) Alzheimer's disease: a disorder of cortical cholinergic innervation. *Science,* 219:1184-1190.

Craig, J. (1964) *Craig's rules of historical evidence 1600; History and theory, studies in the philosophy of history.* Hague: Mounton.

Cramer, P.E., Cirrito, J.R., Wesson, D.W., Lee, C.Y., Karlo, J.C., Zinn, A.E., Casali, B.T., Restivo, J.L., Goebel, W.D., James, M.J. and Brunden, K.R. (2012) ApoE-directed therapeutics rapidly clear beta-amyloid and reverse deficits in AD mouse models. *Science,* 335(6075):1503-1506.

Creasey, H. and Rapport, S.I. (1985) The Ageing Human Brain. *Annals of Neurology*, 17:2-10.

Creutzfeldt, H.G. (1920) Ueber eine eigenartrige herdfoerminge Erkrankung des Zentralnervensystems. *Zeitschrift für die Gesamte Neurolie und Psychiatrie,* 57:1-18.

Critchley, M. (1931) The neurology of old age, part III. *The Lancet,* 1:1331-1337.

Crystal, H.A., Dickson, D., Davies, P., Masur, D., Grober, E. and Lipton, R.B. (2000) The relative frequency of dementia of unknown aetiology increases with age and is nearly 50% in nonagenarians. *Archives of Neurology*, 57(5):713-719.

Cullen, W. (1793) *A Synopsis of Medical Nosology*. Philadelphia: Hall.

Cummings, J.L. (1986) Subcortical dementia. Neuropsychology, neuropsychiatry and pathophysiology. *British Journal of Psychiatry,* 149:682-697.

Cunningham, H. (1995) *Children and Childhood in Western Society since 1500.* New York: Longman.

Cutler, N. (1986) Public response: the national politics of Alzheimer's disease. In: Gilhooly, M., Zarit, S. and Birren, J.E. (eds.) *The Dementias: Policy and management*. Englewood Cliffs NJ: Prentice Hall.

Cyck, L.M. and Wright, H.H. (2008) Frontotemporal dementia: its definition, differential diagnosis and management. *Aphasiology,* 22(4):422-444.

Day, G.E. (1849) *Practical treatise on the domestic management and most important diseases of advanced life*. London: Lea Boone.

Davies, C. (1980) Making sense of the census in Britain and the USA: The changing occupational classification and the position of nurses. *Sociological Review,* 28(3):581-609.

Davis, D.H.J. (2004) Dementia: sociological and philosophical constructions. *Social Sciences and Medicine,* 58:369-378.

Davis, S., Byers, S., Nay, R. and Koch, S. (2009) Guiding design of dementia friendly environments in residential care setting: considering the living experiences. *Dementia,* 8(2):185-203.

Davies, E. and Higginson, I.J. (2004) *Better palliative care for older people.* Regional Office for Europe: World Health Organisation.

Davies, P. and Maloney, A.J.R. (1976) Selective loss of central cholinergic neurons in Alzheimer's disease. *Lancet,* ii:1403.

De George, R.T. and De George, F.M. (1972) *The Structuralists: From Marx to Lévi-Strauss*. New York: Anchor books.

De Leon, M.J., Ferris, S.H., Blau, I., George, A.E., Reisberg, B., Kricheff, I.I. and Gershon, S. (1979) Correlations between computerized tomographic changes and behavioural deficits in senile dementia. *The Lancet*, 314(8147): 859-860.

De Leon, M.J., Ferris, S.H., George, A.E. Reosberg, B., Kricheff, I.I. and Gershon, S. (1980) Computerised tomography evaluations of brain-behaviour relationships in senile dementia of the Alzheimer type. *Neurobiology of Ageing,* 1(1):69-79.

De Strooper, B. and Karran, E. (2016) The cellular phase of Alzheimer's disease. Cell, 164(4):603-615.

Dean, M. (1994) *Critical and effective histories: Foucault's methods and historical sociology*. London: Routledge.

Dejerne, J. (1892) Contribution a l'etude anatomoclinique et clinique des différentes varities de cécité verbale. *Compte rendu hebdomadaire des scénances et memoires de la société de biologie*, 4:61-90.

Dello Russo, C., Di Giulio, P,, Brunelli, C., Dimonte, V., Vilani, D., Renga, G. and Toscani, F. (2008) Validation of the Italian version of the discomfort scale – dementia of the Alzheimer type. *Journal of Advanced Nursing,* 64(3):298-304.

Dementia Action Alliance (2010) *National Dementia Declaration.* London: Dementia Action Alliance.

Dening, K.H., Jones, L. and Sampson, E.L. (2011) Advance care planning for people with dementia. *International Psychogeriatrics*, 23(10):1535-1552.

Dening, T. and Babu Sandilyan, M, (2015) Dementia: definitions and types. *Nursing Standard,* 29(37):37-42,

Department of Health (2008) *End of Life Care Strategy: Promoting high quality care for all adults at the end of life*. London: DH.

Department of Health (2009) *Living Well with Dementia: A National Dementia Strategy.* London: DH.

Department of Health (2010) *Quality Outcomes for People with Dementia: Building on the work of the National Dementia Strategy*. London: DH.

Department of Health (2012) *Prime Ministers Challenge on Dementia: Delivering major improvements in dementia care and research by 2015.* London: DH.

Department of Health, Social Services and Public Safety (DHSSPS) (2011) *Improving dementia services in Northern Ireland: a regional strategy.* Belfast: DHSSPS.

Deutsch, J.A. (1971) The cholinergic synapse and the site of memory. *Science,* 174:788-794.

Devanand, D.P, Pradhabab, G., Liu, X., Khandji, A., De Santi, S., Segal, S., Rusinek, H., Pelton, G.H., Honig, L.S., Mayeux, R. and Stern, Y. (2007) Hippocampal and entorhinal atrophy in mild cognitive impairment: prediction of Alzheimer disease. *Neurology,* 68(11):828-836.

Diderot and d'Alembert (1754) Encyclopdédie ou dictionnaire raisonné des sciences, des arts et des métieres, par une société de gens de lettres. Vol 4, A Paris, Briasson, David, Le Bretton Durnad.

Dillman, R. (1990) *Alzheimer's Disease: The concept of the disease and the construction of medical knowledge*. Amsterdam: Study Publishers.

Dillman, R.J.M. (2000) Alzheimer disease: Epistemological lessons from history? In: Whitehouse, P.J., Maurer, K. and Ballenger, J.F. (eds.) *Concepts of Alzheimer Disease. Biological, Clinical and Cultural Perspectives.* London: The John Hopkins University Press, pp.129-157.

Divry, P. (1927) Étude histochimique des plaques séniles. *Journal Belge de Neurologie Psychiatrie,* 9: 643-657.

Dorenlot, P. (2005) Editorial, *Dementia,* 4(4):450-451.

Downs, M. and Bowers, B. (2008) *Excellence in dementia care: research into practice.* Buckingham: Open University.

Downs, M., Capstick, A., Baldwin, P., Surr, C. and Bruce, E. (2009) The role of higher education in transforming the quality of dementia care: dementia studies at the university of Bradford. *International Psychogeriatrics,* 21:S3-S15.

Downs, M., Small, N. and Froggatt, K. (2006) Explanatory models of dementia: links to end-of-life care. *International Journal of Palliative Nursing,* 12(5):209-213.

Drachman, D.A. (1983) How Normal Ageing Relates to dementia: a critique and classification. In: Samuel, D., Algeri, S. and Gershon, S. (eds.) *Ageing of the Brain.* New York: Raven Press, pp. 19-31.

Drachman, D.A. and Leavitt, J. (1974) Human memory and the cholinergic system, a relationship to ageing? *Archives of Neurology,* 30:113-121.

Du Laurens, A. (1938) *A Discourse of the Preservation Of Sight: Of Melancholike Diseases; of Rheumes and of Old Age.* (trans. Surphlet, R.) London: The Shakespeare Association.

Dubois, B., Feldham, H.H., Jacova, C., De Kosky, S.T., Barberger-Gateau, P., Cummings, J., Delacourte, A., Galasko, D., Gauthier, S., Jicha, G. and Meguro, K. (2007) Research criteria for the diagnosis of Alzheimer's disease: revising the NINCDS-ADRDA criteria. *The Lancet Neurology*, 6(8):734-746.

Dubois, B., Feldman, H.H., Jacova, C., Cummings, J.L., DeKosky, S.T., Barberger-Gateau, P., Delacourte, A., Frisoni, G., Fox, N.C., Galasko, D. and Gauthier, S. (2010) Revising the definition of Alzheimer's disease: a new lexicon. *The Lancet Neurology,* 9(11):1118-1127.

Dunglison, R. (1842) *The Practice of Medicine*. Philadelphia: Lee and Blanchard

Dunphy, L., Proctor, G., Bartlett, R., Haslam, M. and Wood, C. (2010) Reflections and learning from using action learning sets in a healthcare education setting. *Action Learning: Research and Practice,* 7(3):303-314.

Durkheim, E. (1879/1985) *Suicide: A study in sociology.* (trans. Thompson, K. 1985) London: Routledge and Kegan Paul.

Dyson, S. and Brown, B. (2006) *Social theory and applied social research.* Berkshire: Open University Press.

Ebers Papyrus (1930 [1500 BCE approx.]) (trans. Bryan), *The Papyrus Ebers.* Herts: The Garden City Press Ltd.

Edwin Smith Surgical Papyrus (1930 [2000 BCE]), (trans. Brested, J.) *The Edwin Smith Papyrus*. Chicago: University of Chicago Press.

Égerházi, A., Berecz, R., Bartók, E. and Degrell, I. (2007) Automated neuropsychological test battery (CANTAB) in mild cognitive impairment and Alzheimer's disease. *Progress on Neuro-Psychopharmacology and Biological Psychology,* 31(3):746-751.

Eitinger, L. (1954) Presenile dementia (Alzheimer's and Pick's disease). *Acta Psychiatrica Scandinavica,* 29(4):411-421.

Elliotson, J. (1832) St Vitus's dance. *Lancet*, i:162-165.

Elton, G.R. (1967) *The Practice of History*. Sydney: UP.

Elton, G.R. (1991) *Return to Essentials. Some Reflections on the Present State of Historical Study*. Cambridge: Cambridge University Press.

Elvish, R., Burrow, S., Cawley, R., Harney, K., Graham, P., Pilling, M., Gregory, J., Roach, P., Fossey, J. and Keady, J. (2014) “Getting to know me”: the development and evaluation of a training programme for enhancing skills in care of people with dementia in general hospital settings. *Aging and Mental Health,* **18**(4): 481-488.

Engelhardt, E. and Grinberg, L.T. (2015) Alzheimer and vascular brain disease: senile dementia. *Dementia and Neuropsychology,* 9(2): 184-188.

Erikson, K.I., Voss, M.W., Prakash, R.S., Basak, C., Szabo, A., Chaddock, L., Kim, J.S., Heo, S., Alves, A., White, S.M., Wojcicki, T.R., Mailey, E., Vieira, V.J., Martin, S.A., Pence, B.D., Woods, J.A., McAuley, E. and Kramer, A.F. (2011) Exercise training increases size of hippocampus and improves memory. *Proceedings of the National Academy of Sciences*, 108(7):3017-3022.

Erzigkeit, H. (1989) The SKT: a short cognitive performance test as an instrument for the assessment of clinical efficacy of cognition enhancers. In: Bergener, M. and Reisberg, B. (eds.) *Diagnosis and treatment of senile dementia.* Berlin: Springer-Verlag, pp.164-174.

Emmison, M. and Smith, P. (2000) *Researching the visual.* London: Sage

Employers for Carers (2014) *Supporting employees who are caring for someone with dementia*. London: Carers UK.

Esquire, J. (1829) *Della Alienazione Mentale o della Pazzia in genere e in ispecie.* Milano: Felice Rusconi.

Esquirol, J.E.D. (1838) Traité des Maladies Mentales. Paris: Bailliere. (trans. Hunt, E.K. (1845) *Mental Maladies – a treatise on insanity.* Philadelphia: Lea and Blanchard.

Esquirol, E. (1814) Démence. In: *Dictionnaire des Sciences.* Médicales XLVI-I.

Esquirol, E. (1805) *Des passions.* Paris: Didot Jeune.

Estes, C.L. and Biney, E.A. (1989) The bio medicalisation of ageing: dangers and dilemmas. *The Gerontologist,* 29(5):587-596.

Ettema, T.P., Droes, R.M., de Lange, J., Mellenbergh, G.J. and Ribbe, M.W. (2007) QUALIDEM: Development and evaluation of a dementia specific quality of life instrument. *International Journal of Geriatric Psychiatry,* 22(5):424-430.

Evans, R.J. (2000 [1997]) *In defence of history*. London: Granta Books.

Falconer, W.A. (1964) *Cicero. De senectute, de amicitia, de divination*. (trans. Falconer, W.A.) London: William Heinemann.

Falk, H., Oersson, L.O. and Wijk, H. (2007) A psychometric evaluation of a Swedish version of the quality of life in late-stage dementia (QUALID) scale. *International Journal of Geriatric Psychiatry,* 22(6):549-556.

Farina, N., Rusted, J. and Tablet, N. (2014) The effect of exercise interventions on cognitive outcome in Alzheimer's disease: a systematic review. *International Psychogeriatrics*, 26(1):9-18.

Feldham, S.M. (1998) *Please don't wish me a merry Christmas: a critical history of the separation of Church and State.* London/New York: New York University Press.

Ferri, C.P., Prince, M., Brayne, C., Brodaty, H., Fratiglioni, L., Ganguli, M., Hall, K., Hasegawa, K., Hendrie, H., Huang, Y., Jorm, A., Mathers, C., Menezes, P.R., Rimmer, E. and Scazufca, M. (2005) Global prevalence of dementia: a Delphi consensus study. *Lancet,* 366(21):12-17.

Fernandez-Bouzas, A., Ramirez, H.J., Vázquez, J.Z., Alonso-Vanegas, M. and Mendizabal, R.G. (1992) Brain calcifications and dementia in children treated with radiotherapy and intrathecal methotrexate. *Journal of Neurological Sciences,* 36(4):211-214.

Fernando, M.S. and Ince, P.G. (2004) Vascular pathologies and cognition in a population based cohort of elderly people. *Journal of Neurological Sciences,* 299:136-138.

Fernel, J. (1656) *Universal Medicina, lib III, cap III.* Utrecht: à Ziyll and van Ackersdijck.

Fink, M., Green, M.A. and Bender, M.B. (1952) The Face-Hand test as a sign of organic mental syndrome. *Neurology,* 1:46-58.

Fischer, O. (1907) Miliare nekrosen mit drusigen wucherungen der neurofibrillen, eine regelmässige veränderung der hirnrinde bei seniler demez. *Monatsschrift für Psychiatrie und Neurologie*, 22:361-372.

Fischer, O. (1908) Die histopathologie de presbyophrene. Silzungsbericht deutsch. *Verein Psych Allg Zeitschr f Psych*, 65:500.

Fischer, O. (1910) Die presbiophrene demenz, deren anatomishe grundlage und klinische abgrenzung. *Z Gesamte Neurol Psychiatr,* 3:371-471.

Flechsig, P. (1900) über projections und associations – Zentren des menschlichen gehirens (On projection and association centres of the human brain). *Neurologie Zentralblatt*, 19.

Flechsig, P. (1920) *Anatomie des menschlichen gehirns und rückenmarks auf myelogenetischer grundlage*. Lepzig: Thieme.

Folstein, M.F., Folstein, S.E. and McHugh, P.R. (1975) 'Mini-Mental State': a practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research,* 12:189-198.

Förstl, H. (2000) Contributions of German neuroscience to the concept of Alzheimer disease. In: Whitehouse, P.J., Maurer, K. and Ballenger, J.F. (eds.) *Concepts of Alzheimer Disease. Biological, Clinical and Cultural Perspectives.* London: The John Hopkins University Press, pp. 72-82.

Förstl, H. (2005) Uncommon causes of dementia: an historical account. *International Psychogeriatrics,* 17 Suppl 1:S3-15.

Foucault, M. (1967 [1961]) *Madness and civilisation: a history of insanity in the age of reason* (trans. Sheridan, A.M.) London: Tavistock Publications Limited.

Foucault, M. (1970 [1966]) *The Order of Things* (trans. Sheridan, A.M.) London: Tavistock Publications Limited.

Foucault, M. (1972 [1969]) *The Archaeology of Knowledge.* (trans. Sheridan, A.M.) London: Tavistock Publications Limited.

Foucault, M. (1973 [1963]) *Birth of the clinic. An Archaeology of medical Perception.* (trans. Sheridan, A.M.). London: Tavistock Publications Limited

Foucault, M. (1977 [1975]) *Discipline and Punish: the birth of the prison.* (trans. Sheridan, A.M.) Vintage: New York.

Foucault, M. (1978 [1976]) *The history of sexuality, Volume 1: an introduction.* (trans. Sheridan, A.M.) New York: Vintage Press.

Foucault, M. (1980) Power and Strategies. In: Gordon, C. (eds.) *Power/Knowledge: selected interviews and other writings 1972-1977*. London: Harvester Wheatsheaf, pp. 134-145.

Foucault, M. (1981) The order of discourse. In: Young, R. (ed.) *Untying the text: a post-structuralist reader*. London: Routledge and Kegan Paul.

Foucault, M. (1983) Structuralism and post-structuralism. *Telos,* 55:195-211.

Foucault, M. (1984) Polemics, politics, and problematizations. In: Rabinow, P. (ed.) *The Foucault Reader*. New York: Penguin, pp. 381-390.

Foucault, M. (1989a) What our present is. In: Lotringer, S. (ed.) *Foucault Live: Interviews 1966-1984*. New York: Semiotexte.

Foucault, M. (1989b) Power affects the body. In: Lotringer, S. (ed.) *Foucault Live: Interviews 1966-1984*. New York: Semiotext.

Foucault, M. (1989c) Prison talk. In: Lotringer, S. (ed.) *Foucault Live: Interviews 1966-1984*. New York: Semiotexte.

Foucault, M. (1991) *Remarks on Marx.* New York: Semiotext.

Foucault, M. (1997) The ethics of the concern of a self as a practice of freedom. In: Rabinow, P. (ed.) *Michel Foucault: the essential works*. *Volume 1*. London: Allen Lane

Fox, P.J. (1989) From senility to Alzheimer's disease: the rise of the Alzheimer's movement. *Milbank Quarterly*, 67(1):58-102.

Fox, P.J. (1999) Defining dementia: social and historical background of Alzheimer disease. *Genetic Testing,* 3(1):13-19.

Fried, L., Tangen, C., Walston, J., Newman, A.B., Hirsch, C., Gottinder, J., Seeman, T., Tracy, R., Kop, W.J., Burke, G. and McBurnie, M.A. (2001) Frailty in older adults: evidence for a phenotype. *Journal of Gerontology: Medical sciences,* 56A:146-156.

Froggatt, A. (1988) Self-awareness in early dementia. In: Gearing, B., Johnson, M. and Heller, T. (eds.) *Mental Health Problems in Old Age: a reader.* Chichester: John Wiley and Sons, pp. 131-138.

Fruhauf, C.A. (2007) Innovative practice helping students understand ageing and dementia: an innovative program. *Dementia,* 6(1):157-162.

Fukui, T. (2014) Historical review of academic concepts of dementia in the world and Japan: with a short history of representative diseases. *Neurocase,* Mar 7 [Electronic Publication].

Fuller, S.C. (1912) Alzheimer's disease (senium praecox): the report of a case and review of published cases. *Journal of Nervous and Mental Diseases,* 39:440-536.

Fuller, S.C. and Klopp, H.I. (1912) Further observations on Alzheimer disease. *American Journal of Insanity,* 69:17-29.

Gajdusek, D.C. (1964) Attempt to demonstrate a transmissible agent in Kuru, amyotrophic lateral sclerosis, and the sub-acute and chronic nervous system degeneration of man. *Nature*, 204(4955):257-259.

Gajdusek, D.C. and Zigas, V. (1957) Degenerative disease of the central nervous system in New Guinea; the endemic occurrence of “kuru” in the native population. *New England Journal of Medicine*, 257:974-948.

Gale, K.N., Heath, G., Cameron, E., Rashid, S. and Redwood, S. (2013) Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology,* 13(117):1-8.

Galen, C. (1821-1833 translation) De symptomatum differentiis liber. In: Kuhn, C.G. (ed.) *Opera omnia* (Volume 7). Leipzig: Knobloch, pp. 200-201.

Galindo-Garre, F., Hedricks, S.A., Volicer, L., Smalbrugge, M., Hetogh, C.M.P.M. and van der Stern, J.T. (2013) The BAN-S to assess dementia severity in advanced dementia: a non-parametric item response analysis and a study of the validity. *American Journal of Alzheimer’s Disease and other Dementias,* 29(1):51-68.

Games, D., Adams, D., Alessandrini, R., Barbour, R., Berthelette, P., Blackwell, C., Carr, T., Clemens, J., Donaldson, T. and Gillespie, F. (1995) Alzheimer-type neuropathology in transgenic mice overexpressing $V_{717}F$ beta-amyloid precursor protein. *Nature,* 373(6514): 523-527.

Ganguli, M., Blacker, D., Blazer, D.G., Grant, I., Jeste, D.V., Paulsen, J.S., Petersen, J.S., Petersen, R.C. and Sachdev, P.S. (2011) Classification of neurocognitive disorders in DSM-5: a work in progress. *American Journal of Geriatric Psychiatry,* 19:205-210.

Gellerstedt, N. (1933) Zur kenntnis der hirnveranderungen bei der normalen altersinvolution. *Upsala Lakareforenings Forhandingar,* 38:193-408.

George, D., Stuckey, H., Dillon, C. and Whitehead, M.M. (2011a) Impact of participation in time slips, a creative group-based storytelling program, on medical student attitudes towards persons with dementia: a qualitative study. *The Gerontologist,* 51(5):699-703.

George, D., Whitehouse, P.J. and Ballenger, J. (2011b) The evolving classification of dementia: placing the DSM-V in a meaningful historical and cultural context and pondering the future of “Alzheimer’s”. *Culture, Medicine and Psychiatry,* 35(3):417-435.

Gibb, W.R.G., Esiri, M.M. and Lees, A.J. (1987) Clinical and pathological features of diffuse cortical Lewy body disease (Lewy body dementia). *Brain,* 110:1131-1153.

Gibson, E.T. (1918) A clinical summary of 10 cases of mental disorder of unknown etiology arising in the fifth and sixth decade. *American Journal of Insanity,* 75:221-249.

Gilliard, J., Means, R., Beattie, A. and Darker-White, G. (2005) Dementia care in England and the social model of disability. *Dementia: International Journal for Social Research and Practice,* 4(4):571-586.

Glenner, G.C. and Wong, C.W. (1984a) Alzheimer’s disease: initial report of the purification and characterization of a novel cerebrovascular amyloid protein. *Biochemical and Biophysical Research Communications,* 120(3):885-890.

Glenner, G.G. and Wong, C.W. (1984b) Alzheimer's disease and Down’s syndrome: Sharing of a unique cerebrovascular Amyloid fibril protein. *Biochemical and Biophysical Research Communications,* 122(3):1131-1135.

Go, R.C., Duke, L.W., Harrell, L.E., Cody, H., Bassett, S.S., Folstein, M.F., Albert, M.S., Foster, J.L., Sharrow, N.A. and Blacker, D.(1997) Development and validation of a structured telephone interview for dementia (STIDA): the NIMH genetics initiative. *Journal of Geriatric Psychiatry and Neurology,* 10(4):161-167.

Goate, A., Chartier-Harlin, M., Mullan, M., Brown, J., Crawford, F., Fidani, L., Giuffra, L., Haynes, A., Irving, N., James, L., Mont, R., Newton, P., Rooke, K., Roques, P., Talbot, C., Pericak-Vance, M., Roses, A., Williamson, R., Rossor, M., Owen, M. and Hardy, J. (1991) Segregation of a missense mutation in the

amyloid precursor protein gene with familial Alzheimer's disease. *Nature,* 349(6311):704-706.

Godbolt, A.K., Cancelliere, C., Hincapié, C.A. (2014) Systematic review of the risk of dementia and chronic cognitive impairment after mild traumatic brain injury: results of the international collaboration on mild traumatic brain injury prognosis. *Archives of Physical Medicine and Rehabilitation,* 93(3):Suppl S245-S256.

Goetz, C.G., Emre, M. and Dubois, B. (2008) Parkinson's disease dementia: definitions, guidelines, and research perspectives in diagnosis. *Annals of Neurology,* 64(Suppl.):S81-S92.

Goldgaber, D., Lerman, M., McBride, O.W., Saffiotti, U. and Gajdusek, D.C. (1987) Characterization and chromosomal localization of a cDNA encoding brain amyloid of Alzheimer's disease. *Science,* 235(4791):877-880.

Goldman, R. (1992) Reading ads socially. London: Routledge.

Goldsmith, M. (1996) Hearing the voice of people with dementia: opportunities and obstacles. London: Jessica Kingsley.

Gottfies, C.G. (1991) Classifying organic mental disorders and dementia: a review of historical perspectives. *International Psychogeriatrics,* 3(Suppl):9-17.

Gottfries, C.G., Brane, G. and Steen, G. (1982) A new rating scale for dementia syndromes. *Gerontology,* 28:20-31.

Gottschalk, L., Kluckhohn, C. and Angell, R. (1945) *The use of personal documents in history, anthropology and sociology*. New York: Social Science Research Council.

Gowers, W.R. (1902) Abiotrophy. *Lancet*, ii:1004.

Greenfield, J.G. (1954) *The spino-cerebellar degenerations*. Oxford: Blackwell.

Grijalvo-Perez, A.M. and Litvan, I. (2014) Corticobasal degeneration. *Seminars in Neurology*, 34(2):160-173.

Grinberg, L.T. and Heinsen, H. (2010) Toward a pathological definition of vascular dementia. *Journal of the Neurological Sciences,* 299:136-138.

Grob, G.N. (1983) *Mental illness and American society, 1875-1940*. Princeton NJ: Princeton University Press.

Guest, G., MacQueen, K.M. and Namey, E.E. (2012) *Applied thematic analysis.* Thousand Oaks, CA: Sage.

Gurman, G. (1979) *The "Fixed Period" Controversy*. New York: Arno Press.

Gubrium, J.F. (1986) *Oldtimers and Alzheimer's: The descriptive organisation of senility.* Greenwich, Connecticut and London: JAI Press.

Guiraud, P. (1943) Evolution de l'idée de démence. *Ann. Méd-Psychol*, 101:186-199.

Haber, C. (1983) *Beyond sixty-five: the dilemma of old age in American's past*. Cambridge: Cambridge University Press.

Hachinski, V. (2008) Shifts in thinking about dementia. *Journal of the American Medical Association,* 300:2171-2173.

Hachinski, V.C., Lassen, N.A. and Marshall, J. (1974) Multi-infarct dementia: a cause of mental deterioration in the elderly. *Lancet,* ii:207-210.

Hacking, I. (1986) Making up people. In: Heller, T.L., Sosna, M. and Wellberry, D.E. (eds.) *Reconstructing individualism*. California: Stanford University Press, pp. 222-236.

Hacking, I. (1996) The looping effects of human kinds. In: Sperber, D., Premack, D. and Premack, A. (eds.) *Casual Cognition. An interdisciplinary debate.* Oxford: Oxford University Press, pp.351-383.

Hacking, I. (2004) *Historical ontology.* London: Harvard University Press.

Hacking I (2007) Kinds of people: moving targets. *Proceedings of the British Academy,* 151: 285-318.

Hacking, I. (2009) The guidance of culture: Giulio Pretoi's 1972 debate with Michel Foucault Revisited. *Diogenes,* 224:81-85.

Hadlow, W.J. (1959) Scrapie and kuru. *Lancet*, ii:289-290.

Hakim, C. (1980) Census reports as documentary evidence: the census commentaries 1801-1951. *Sociological Review,* 28(3):551-580.

Hakola, H.P. (1972) Neuropsychiatric and genetic aspects of a new hereditary disease characterising progressive dementia and lipomembranous polycystic osteodysplasia. *Acta Psychiatr Scand,* Suppl. 232: 1-173.

Hall, S. (1991) Reconstruction work: images of post-war black settlement. In: Spence, J. and Holland, P. (eds.) *Family Snaps: The Meaning of Domestic Photography.* London: Vintago Press.

Hall, S. (1992) The West and the Rest: Discourse and Power. In: Hall, S. and Gieben, B. (eds.) *Formations of modernity.* Cambridge: Polity Press, pp. 275-331.

Hall, S., Petkova, H., Tsouros, A.D., Constantini, M. and Higginson, I.J. (2004) *Palliative Care for Older People: Better Practices.* Denmark: WHO.

Hallert, C. (1997) Historical texts: factors affecting their interpretation. *Nurse Researcher,* 5(2):61-71.

Halpert, B.P. (1983) Development of the term "senility" as a medical diagnosis. *Minnesota Medicine,* 66(7):421-424.

Hamilton, P. (1985) Editor's Foreword (Series Editor, Key Sociologists). In: Smart, B. (ed.) *Michel Foucault*. Ellis Horwood and Tavistock, pp.7-9.

Hannah, J.A. (1936) Case of Alzheimer's disease with neuropathological findings. *Canadian Medical Association Journal*, 35:361-366.

Hanson, B.G. (1991) Parts, players and "patienting": The social construction of senile dementia. *Family Systems Medicine,* 9(3):267-274.

Harding, N. and Palfrey, C. (1997) *The social construction of dementia: confused professionals?* London: Jessica Kingsley.

Hardy, J. (2009) The amyloid hypostudy for Alzheimer's disease: a critical reappraisal. *Journal of Neurochemistry,* 110(4):1129-1134.

Hare, M. (1978) Clinical checklist for diagnosis of dementia. *British Medical Journal,* 2:266-267.

Harrell, L.E., Marson, D., Chatterjee, A. and Parrish, J.A. (2000) The severe mini-mental state examination: a new neuropsychological instrument for the bedside assessment of severely impaired patients with Alzheimer's disease. *Alzheimer's Disease and Associated Disorders,* 14:168-175.

Hartley, D. (1834) *Observations on man, his frame, his duty and his expectations.* London: Thomas Tegg.

Hasselbach, S., Baloyannis, S., Denislic, M., Dubois, B., Oertel, W., Rossor, M., Tsiskaridze, A. and Waldemar, G. (2007) Education and training of European neurologists in dementia. *European Journal of Neurology*, 14(5):505-509.

Heaton, J. (1999) The gaze and visibility of the carer: a Foucauldian analysis of the discourse of informal care. *Sociology of Health and Illness,* 21(6):759-777.

Heaton, R.K., Chelune, G.J., Talley, J.L., Kay, G.G. and Curtis, G. (1993) *Wisconsin Card Sorting Test Manual*. *Revised and expanded.* Odessa, FL: Psychological Assessment Resources.

Hendricks, S.A., Smalbrugge, M., Hertogh, C.M. and van der Steen, J.T. (2014) Dying with dementia: symptoms, treatment and quality of life in the last week of life. *Journal of Pain Symptom Management,* 47(4):710-720.

Heston, L.L., Mastri, A.R., Anderson, V.E. and White, J. (1981) Dementia of the Alzheimer type. Clinical genetics, natural history, and associated conditions. *Archives of General Psychiatry,* 39(10):1085-1090.

Herskovits E (1995) Struggling over subjectivity: Debates about the “self” and Alzheimer’s disease. *Medical Anthropology Quarterly,* 9(2):146-164.

Hicks, R.D. (1907) Aristotelis de anima. Cambridge: Cambridge University Press.

Higher Education Dementia Network (HEDN) (2013) A curriculum for UK dementia education. London: Dementia UK.

Hilton, C. (2015) Psychiatrists, mental health provision and ‘senile dementia’ in England, 1940s-1979. *History of Psychiatry,* 26(2):182-199.

Hirano, A. and Kurland, L.T. (1961) Parkinson-dementia complex, an endemic disease on the island of Guam. *Brain,* 84:642-679.

Hirsch, M. (1997) *Family Frames: Photography, Narratives, and Post memory.* Cambridge MA: Harvard University Press.

Hock, C., Konietzko, U., Streffer, J.R., Tracy, J., Signorell, A., Müller-Tilmanns, B., Lemke, U., Henke, K., Moritz, E., Garcia, E., Wollmer, M.A., Umbricht, D., de Quervain, D.J.F., Hofmann, M., Maddalena, A., Papassotiropoulos, A. and Nitsch, R.M. (2003) Antibodies against beta-amyloid slow cognitive decline in Alzheimer’s disease. *Neuron,* 38(4):547-554.

Hodges, J.R. (2006) Alzheimer’s centennial legacy: origins, landmarks and the current status of knowledge concerning cognitive aspects. *Brain,* 129:2811-2822.

Hodkinson, M. (1972) Evaluation of a mental test score for assessment of mental impairment in the elderly. *Age and Ageing,* 1:233-238.

Hoefferle, C. (2011) *Essential historiography reader.* Boston: Pearson.

Hofmann, M., Hock, C., Kuhler, A. and Muller-Spahn, F. (1996) Interactive computer-based cognitive training in patients with Alzheimer’s disease. *Journal of Psychiatric Research,* 30: 493-501.

Holland, D., Brewer, J.B., Hagler, D.J., Fennema-Notestine, C. and Dale, A.M. (2009) Subregional neuroanatomical change as a biomarker for Alzheimer's disease. *Proc Natl Acad Sci USA,* 106:20954-20959.

Holmes, C. (2013) Review: a systemic inflammation and Alzheimer's disease. *Neuropathology and Applied Neurobiology,* 39(1):51-68.

Holstein, M. (1997) Alzheimer's disease and senile dementia, 1885-1920: An interpretive history of disease negotiation. *Journal of Ageing Studies,* 11(1):1-13.

Holstein, M. (2000) Ageing, culture, and the framing of Alzheimer disease. In: Whitehouse, P.J., Maurer, K. and Ballenger, J.F. (eds.) *Concepts of Alzheimer Disease. Biological, Clinical and Cultural Perspectives.* London: The John Hopkins University Press, pp.158-180.

Hughes, C. (1887) Insanity defined on the basis of disease. *The Alienist and Neurologist,* 20:170-174.

Hunter, R. and Macalpine, I. (1964) *Three hundred years of psychiatry (1535-1860). A history presented in selected English texts.* London: Oxford University Press.

Iacono, D., Markesbery, W.R., Gross, M., Pletnikova, O., Rudow, G., Zandi, P. and Troncosco, J.C. (2009) The Nun study. Clinically silent AD, neuronal hypertrophy and linguistic skills in early life. *Neurology,* 73:665-673.

Imai, Y. and Hasegawa, K. (1994) The revised Hasegawa's dementia scale (HDS-R)- evaluation of its usefulness as a screening test for dementia. *Journal of Hong Kong College of Psychiatry,* 4:20-24.

Innes, A. (2009) *Dementia studies.* London: Sage.

Inouye, S.K., Robinson, J.T., Groehlich, T.E. and Richardson, E.D. (1998) The time and change test: a simple screening test for dementia. *Journal of Gerontology,* 54A:M281-M286.

Irvine, A.B., Beaty, J.A., Seeley, J.R. and Bourgeois, M. (2013) Use of a dementia training designed for nurse aides to train other staff. *Journal of Applied Gerontology,* 32: 936-951.

Isaacs, B. and Akhtar, A. (1972) The SET Test: a rapid test of mental function in old people. *Age and Ageing,* 1: 222-226.

Jack, C.R. Jr. (2012) Alzheimer disease: new concepts on its neurobiology and the clinical role imaging will play. *Radiology,* 263(2): 344-361.

Jack, C.R. Jr., Knopman, D.S., Jagust, W.J., Shaw, L.M., Aisen, P.S., Weiner, M.W., Petersen, R.C. and Trojanowski, J.Q. (2010) Hypothetical model of dynamic biomarkers of the Alzheimer's pathological cascade. *Lancet Neurol,* 9(1):119-128.

Jacob, A. (1921) Ueber eigenartige erkrankungen des Zentralnervensystem mit bemerkenertem anatomischem Befund (spastiche Pseudosclerose-Encephalomyelopathie mit disseminierten Degenerationsherden). *Deutsche Zeitschrift für Nervenheilkunde*, 70: 132-138.

Jacobs, J.W., Bernhard, M.R., Delgado, A., and Strain, J.J. (1977) Screening for organic mental syndromes in the medically ill. *Annals of Internal Medicine,* 86:40-46.

Jacoby, R.J. and Levy, R. (1980) Computed tomography and the elderly: II. Senile dementia: diagnosis and functional impairment. *British Journal of Psychiatry*, 136:256-269.

Jacqmin-Gadda, H., Fabrigoule, C., Commenges, D., Letenneur, L. and Dartignes, J.F. (2000) A cognitive screening battery for dementia in the elderly. *Journal of Clinical Epidemiology,* 53:980-987.

Jäger, S. and Maier, F. (2009) Theoretical and methodological aspects of Foucauldian critical discourse analysis and dispositive analysis. In: Wodak, R. and Meyer, M. (eds.) *Methods of Critical Discourse Analysis*. London: Sage, pp. 34-61.

Jagust, W. (2006) Positron emission tomography and magnetic resonance imaging in the diagnosis and prediction of dementia. *Alzheimer's Dement,* 2(1): 36-42.

Jameson, F. (1981) *The Political Unconsciousness: Narrative as a socially symbolic act.* London: Methuen.

Jameson, T. (1811) *Essays on the changes of the changes of the human body and its different ages.* London: Longman.

Jaunmuktane, Z., Mead, S., Ellis, M., Wadsworth, J.D., Nicoll, A.J., Kenny, J., Launchbury, F., Linehan, J., Richard-Loendt, N., Walker, A.S., Rudge, P., Collimge, J. and Brandner, S. (2015) Evidence for human transmission of amyloid-ß pathology and cerebral amyloid angiopathy. *Nature,* 525(7568): 247-250.

Javadi, M. and Zarea, K. (2016) Understanding thematic analysis and its pitfall. *Journal of Client Care,* 1(1): 33-39.

Jellinger, K.A. (2006) Alzheimer 100 – highlights in the history of Alzheimer research. *Journal of Neural Transmission,* 113(11):1603-1623.

Jellinger, K.A. (2007) The enigma of vascular cognitive disorder and vascular dementia. *Acta Neuropathol,* 113:349-388.

Jellinger, K.A. (2009) Criteria for the neuropathological diagnosis of dementing disorders: routes out of the swamp? *Acta Neuropathol,* 117:101-110.

Jenkins, K. (1995) *On 'What is History?' From Carr and Elton to Rory and White.* London: Routledge.

Jicha, G.A. and Carr, S.A. (2010) Conceptual evolution in Alzheimer's disease: implications for understanding the clinical phenotype of progressive neurodegenerative disease. *Journal of Alzheimer's Disease,* 19:253-272.

Jones, W.H.S. (1923) *Hippocrates, with an English translation.* London: William Heinman.

Jordan, A., Regmard, C., O'Brien, J.T. and Hughes, J.C. (2012) Pain and distress in advanced dementia: choosing the right tools for the job. *Palliative Medicine,* 26(7):873-878.

Kaf, W., Barboa, L., Fisher, B. and Snavely, L.A. (2011) Interdisciplinary service learning experience for audiology and speech language pathology students working with adults with dementia. *American Journal of Audiology,* 20:S241-249.

Kahn, R.L., Goldfarb, A.I., Pollack, M. and Peck, A. (1960) Brief objective measures for the determination of mental status in the aged. *American Journal of Psychiatry,* 117:326-328.

Kang, J.E., Lemaire, H.G., Unterbeck, A., Salbum, J.M., Masters, C.L., Grzeschil, K.M., Multhaup, G., Beyreuther, K. and Müller-Hill, B. (1987) The precursor of Alzheimer's disease amyloid A_4 protein resembles a cell-surface receptor. *Nature,* 325(6106):733-736.

Kang, J.E., Lim, M.M., Bateman, R.J., Lee, J.J., Smyth, L.P., Cirrito, J.R., Fujiki, N., Nishino, S. and Holtzman, D.M. (2009) Amyloid-ß dynamics are regulated by orexin and the sleep-wake cycle. *Science,* 326 (5955): 1005-1007.

Karch, C.M., Cruchaga, C. and Goate, A. (2014) Alzheimer's disease genetics: from the bench to the clinic. *Neuron,* 83(1):11-26.

Kassel, V. (1965) Senility – a definition. *Rocky Mountain Medical Journal,* 62(11):51-52.

Katz, S. (1996) *Disciplining old age: the formation of gerontological knowledge.* Charlottesville: University Press of Virginia.

Katz, S., Ford, A.B., Moskowitz, R.W., Jackson, B.A. and Jaffe, M.W. (1963) Studies of illness in the aged. The index of ADL: A standardized measure of biological and psychosocial function. *Journal of the Medical Association,* 185: 914-919.

Katzman, R. (1976) Editorial: the prevalence and malignancy of Alzheimer's disease. A major killer. *Archives of Neurology,* 33(4):217-218.

Katzman, R. (1993) Education and the prevalence of dementia and Alzheimer's disease. *Neurology,* 43:13-20.

Katzman, R. and Bick, K.L. (2000) The rediscovery of Alzheimer disease during the 1960s and 1970s. In: Whitehouse, P.J., Maurer, K. and Ballenger, J.F. (eds.) *Concepts of Alzheimer Disease. Biological, Clinical and Cultural Perspectives. London:* The John Hopkins University Press, pp. 104-114.

Katzman, R., Bown, T., Fuld, P., Peck, A., Schechter, R. and Schimmel, H. (1983) Validation of a short orientation-memory-concentration test of cognitive impairment. *American Journal of Psychiatry,* 140:734-739.

Katzman, R. and Karasu, K. (1975) Differential diagnosis of dementia. In: Fields, W. (ed.) *Neurological and sensory disorders in the elderly.* New York: Stratton Intercontinental Medical Book Corp.

Kawashima, R., Okita, K., Yamazaki, R., Tajima, N., Yoshida, H., Taira, M., Iwata, K., Sasaki, T., Maeyama, K., Usui, N. and Sugimoto, K. (2005) Reading aloud and arithmetic calculation improve frontal function of people with dementia. *The Journals of Gerontology,* 60(3):380-384.

Kelley, C. (2016) Confusion about dementias in long-term care. *The Journal for Nurse Practitioners,* 12(8):e369-e370.

Kesslak, J.P., Niclaul, K. and Sandman, C. (1997) Memory training for individuals with Alzheimer's disease improves name recall. *Alzheimer's Research*, 3:151-157.

Keuck, L. (2018) History as a biomedical matter: recent reassessments of the first cases of Alzheimer's disease. *History and Philosophy of the Life Sciences,* 40: 10 [26 page document non-numbered].

Kidd, M. (1963) Paired helical filaments in electron microscopy of Alzheimer's disease. *Nature,* 197:192-193.

Kitsuse, J.I. and Cicourel, A.V. (1963) A note on the uses of official statistics. *Social Problems,* 11(2):131-139.

Kitwood, T. (1993a) Discover the person, not the disease. *Journal of Dementia Care,* 1(1):16-17.

Kitwood, T. (1993b) Person and process in dementia. *International Journal of Geriatric Psychiatry,* 8(7):541-545.

Kitwood, T. (1995) Dementia. In: Berrios, G. and Porter, R. (eds.) *A history of clinical psychiatry – the origin of psychiatric disorders*. London: The Athlone Press, pp 63-71.

Kitwood, T. (1997) *Dementia reconsidered.* Buckingham: Open University Press.

Klassen, B.T. and Ahlskog, J.E. (2011) Normal pressure hydrocephalus: how often does the diagnosis hold water? *Neurology,* 77(12):1119-1125.

Knapp, M., Prince, M., Albanese, E., Banerjee, S., Dhanasiri, S., Fernandez, J-L., Ferri, C., McCrone, P., Snell, T. and Stewart, R. (2007) *Dementia UK: The full report.* London: Alzheimer's Society.

Knifton, C. (2009) Dementia. In: McVeigh, H. (ed.) *Fundamental aspects of long-term conditions*. Quay Books, pp.153-176.

Knifton, C., Thompson, R., Tullo, E., Waugh, A., Surr, C., Read, K. and Innes, A. (2014) Making a difference in dementia education. *The Journal of Dementia Care,* 22(4):18-21.

Kokmen, E. (1984) Dementia-Alzheimer Type. *Mayo cline Proc*. January, 59:36.

Korsakov, S.S. (1887) *Ob Alkoholnom Paralichie.* Moscow: Kushnereff.

Kosaka, K., Oyanagi, S., Matsuchita, M. and Hori, A. (1976) Pre-senile dementia with Alzheimer – Pick – and Lewy-body changes. *Acta Neuropathologica,* 36(3): 221-233.

Koss, E., Ober, B.A., Delis, D.C. and Friedland, R.P. (1984) The Stroop colour-word test: indicator of dementia severity. *International Journal of Neuroscience,* 24:53-61.

Kotsovsky, D. (1929) The origin of senility. *American Journal of Physiology,* 90:419-420.

Kraepelin, E. (1899) *Compendium der Psychiatrie.* (6th ed.) Lepzig: Abel.

Kraeplin, E. (1912 [1904]) *Lehrbuch der Psychiatrie.* (7th ed.) Lepzig: Barth (trans. Diefendorf, A.R. (1912) Clinical Psychiatry. New York: MacMillan.

Kraeplin, E. (1910) *Psychiatrie: ein Lehrbuch für Studierende und Ärzte, vol 2. Klinishe Psychiatrie, part 1*. (8th ed.) Leipzig: Barth.

Kraeplin, E. (1962 [1918]) *Hundert jahre psychiatrie*. Berlin: Julius Springer Verlag (trans. Baskin, W.) *One hundred years of psychiatry.* New York: Philosophical Library.

Kral, V.A. (1962) Senescent Forgetfulness: Benign and Malignant. *Canadian Medical Association Journal,* 86(6):257-260.

Kral, V.A. (1978) Benign senescent forgetfulness. *Ageing NY,* 7:47-51.

Kurz, A.F. (2000) The concept of dementia: retain, reframe, rename or replace? *International Psychogeriatrics,* 22(1):37-42.

La Capra, D. (1987) *History and criticism.* New York: Cornell University Press.

Lacey, A. and Luff, D. (2007) *Qualitative research analysis.* The NIHR Research Design service for Yorkshire and the Humber. Available from https://www.rds-yh.nihr.ac.uk/wp-content/uploads/2013/05/0_Qualitative_Data_Analysis_Revision_2009.pdf

Lacey, D. (1999) The evolution of care: a 100-year history of institutionalisation of people with Alzheimer's disease. *Journal of Gerontological Social Work,* 31(3-4):101-131.

Langlois, C.V. and Seignobos, C. (1908) *Introduction to the Study of History*. London: Duckworth.

Lawrence, V., Samsi, K., Murray, J., Harari, D. and Banerjee, S. (2011) Dying with dementia: qualitative examination of end-of-life care. *British Journal of Psychiatry,* 199(5):417-422.

Lefroy, R.B. (2000) The legacy of Alois Alzheimer: an historical perspective. *American Journal of Alzheimer's Disease,* 15(4):252-255.

Lévi-Strauss, C. (1968) *Structural anthropology.* (trans. Jacobson, C. and Schoepf, B.C.). London: Allen Lane.

Lewy, F.H. (1912) Paralysis agitans. I. Pathologische Anatomie. In: Lewandowsky, M. (ed.) *Handbuch der Neurologie (Vol. III)*. Berlin: Springer, pp.920-933.

Lewy, F.H. (1913) Zur pathologischen Anatomie der Paralysis agitans. *Deutsche Zeitschrift für Nervenheilkunde,* 50:50-55.

Liepmann, H. (1905) Die linke hemisphäre und das handelin. *Münch Med Wschr,* 49:2375-2378.

Liepmann, H. (1920) Apraxia. *Ergon der ges Med,* 1:516-543.

Lichteim, L. (1885) On aphasia. *Brain,* 2:433-484.

Lichtenberg, P. and Hedge, K. (2009) Filling a gap for healthcare providers. *Journal of the American Society on Ageing,* 33(1):90-94.

Lissauer, H. (1890) Ein Fal von Seelenblindheit nebst einem Beiträge zur Theorie der selben. *Archivr für Psychiatrie und Nervenkrankheiten*, 21:222-270.

Lloret, A., Fuchsberger, T., Giraldo, E. and Vina, J. (2016) Reductive stress: a new concept in Alzheimer's disease. *Current Alzheimer Research*, 13(2):206-211.

Lock, M. (1993) *Encounters with ageing: Mythologies of menopause in Japan and North America.* Berkeley: University of California Press.

Lock, M. (2013) *The Alzheimer conundrum: entanglements of dementia and ageing.* Oxfordshire: Princeton University Press.

Loeb C (1995) The history of vascular dementia. *Journal of the History of the Neurosciences,* 4(2):121-126.

Lømo, T. (2003) The discovery of long-term potentiation. *Philosophical Transactions of the Royal Society of London B,* 358(1432):617-620.

Love, K. and Pinkowitz, J. (2013) Person-centred care for people with dementia: a theoretical and conceptual framework. *Journal of the American Society on Aging,* 37(3):23-29.

Loveday, B. and Kitwood, T. (1998) Improving dementia care: a resource for training and professional development. London: Hawker Publications.

Lowenberg, K. and Waggoner, R. (1934) Familial organic psychoses (Alzheimer's type). *Archives of Neurology and Psychiatry,* 31:737-754.

Lucci, B. (1998) The contribution of Gaetano Perusini to the definition of Alzheimer's disease. *Italian Journal of Neurological Sciences,* 19(1):49-52.

Luengo-Fernandez, R., Leal, J. and Gray, A. (2010) *Dementia 2010. The economic burden of dementia and associated research funding in the United Kingdom.* London: Alzheimer's Research Trust.

Lusk, B. (1997) Historical methodology for nursing research. *Journal of Nursing Scholarship,* 29(4):355-359.

Lyman, K.A. (1989) Bringing the social back in: A critique of the biomedicalisation of dementia. *Gerontologist,* 29(5):597-605.

Lyon, I.W. (1863) Chronic hereditary chorea. *American Medical Times*, 7:289-290.

Macdonald, K. (2008) Using Documents. In: Gilbert, N. (ed.) *Researching social life.* (3rd ed.) London: Sage publications.

Macintyre, S. (1978) Some notes on record taking and making in an antenatal clinic. *Sociological Review*, 26(3):595-611.

Malamud, W. and Lowenberg, K. (1929) Alzheimer's disease: A contribution to its etiology and classification. *Archives of Neurology and Psychiatry,* 21:805-827

Malik, K. (1996) *The meaning of race. Race, history and culture in Western society.* New York: New York University Press.

Manville, C., Morgan-Jones, M., Henham, M., Castle-Clarke, S., Frearson, M., Gunashekar, S. and Grant, J. (2015) *Preparing impact submissions for REF 2014: an evaluation.* Cambridge: RAND Cooperation.

Maudsley, H. (1880) *The Pathology of Mind.* New York: Appleton.

Mander, B.A., Marks, S.M., Vogel, J.W., Rao, V., Lu, B., Saletin, J.M., Ancoli-Israel, S., Jagust, W.J. and Walker, M.P. (2015) ß-amyloid disrupts human NREM slow waves and related hippocampus-dependent memory consolidation. *Nature Neuroscience,* 18(7):1051-1057.

Manos, P.J. and Wu, R. (1994) The ten point clock test: a quick screen and grading method for cognitive impairment in medical and surgical patients. *International Journal of Psychiatry in Medicine,* 24:229-244.

Marcé, L.V. (1863) Recherches cliniques et anatomo-athologiques sur la démence senile et sur les differences qué la séparante de la paralysie generie. E Thumoret C:11-27.

Mapstone, M., Cheema, A.K., Fiandaca, M.S., Zhong, X., Mhyre, T.R., MacArthur, L.H., Hall, W.J., Fisher, S.G., Peterson, D.R., Haley, J.M., Nazar, M.D., Rich, S.A., Berlau, D.J., Peltz, C.B., Tan, M.T., Kawas, C.H. and Federoff, H.J. (2014) Plasma phospholipids identify antecedent memory impairment in older adults. *Nature Medicine,* 20(4):415-418.

Margolia, G. (1959) Senile cerebral disease: a critical survey of traditional concepts based upon observations with newer technics. *Laboratory Investigations,* 8:335-370.

Markus, H.R. and Kitayama, S. (1991) Culture and the self: implications for cognition, emotional and motivation. *Psychological Review,* 98(2):224-253.

Marshall, J. (1968) Pansies, perverts and macho men: Changing conceptions of the modern homosexual. *Social Problems*, 16:82-192.

Mathews, F.E., Arthur, A., Barnes, L.E., Bond, J., Jagger, C., Robinson, L. and Brayne, C. (2013) A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: results of the Cognitive Function and Ageing Study I and II. *Lancet,* 382(9902):1405-1412.

Marwick, A. (1989) *The Nature of History.* (3rd ed.) London: Palgrave MacMillan.

Marx, K. (1976) *Capital: A critique of political economy*. Harmondsworth: Penguin.

Marx, O.M. (1970) Nineteenth-century medical psychology: Theoretical problems in the work of Griesinger, Meynert, and Wernicke. *Isis*, 61:355-370.

Matsui, Y., Tanizaki, Y., Arima, H., Yonemoto, K., Doi, Y., Ninomiya, T., Sasaki, K., Lida, M., Iwaki, T., Kanba, S. and Kiyohara, Y. (2009) Incidence and survival of dementia in a general population of Japanese elderly: the Hisayama study. *Journal of Neurology, Neurosurgery and Psychiatry*, 80(4):366-370.

Mattis, S. (1976) Mental status examination for organic mental syndrome in the elderly patient. In: Bellak, L. and Karasu, T. (eds.), *Geriatric Psychiatry: a handbook for psychiatrists and primary care physicians.* New York: Grune and Stratton, pp. 77-101.

Matusevich, D. (2009) The social construction of dementia: a hypostudy. *Vertex*, 20(87):379-384.

Maurer, K. and Maurer, U. (1998) *Alzheimer: Das Leben eines Arztes und die Karriere einer Krankheit.* München: Piper.

Maurer, K. (2006) Historical background of Alzheimer's research done 100 years ago. *Journal of Neural Transmission*, 113(11):1597-1601.

Maurer, K. and Hoyer, S. (2006) Alois Alzheimer revisited: differences in origin of the disease carrying his name. *Journal of Neural Transmission,* 113(11): 1645-1658.

Maurer, K. and Maurer, U. (2003) Alzheimer: the life of a physician and the career of a disease. New York: Columbia University Press.

Maurer, K., Volk, S. and Gerbaldo, H. (2000) Auguste D: The history of Alois Alzheimer's first case. In: Whitehouse, P.J., Maurer, K. and Ballenger, J.F. (eds.) *Concepts of Alzheimer Disease. Biological, Clinical and Cultural Perspectives.* London: The John Hopkins University Press, pp.5-29.

Mayer-Gross, W.A. (1944) Arteriosclerotic, senile and presenile psychoses. *Journal of Mental Science,* 1:316-327.

McArthur, J.C., Hoover, D.R., Bacellar, E.N., Cohen, B.A., Becker, J.T., Graham, N.M.H., McArthur, J.H., Selnes, O.A., Jacobson, L.P., Visscher, B.R., Concha, M. and Saah, A. (1993) Dementia in AIDS patients: incidence and risk factors. *Neurology,* 43(11):2245-2252.

McCabe, L. (2008) A holistic approach to caring for people with Alzheimer's disease. *Nursing Standard,* 22(42):50-56.

McCracken, E. (1993) *Decoding Women's Magazines: From Mademoiselle to Ms.* Basingstoke: Macmillan.

McDowell, W.H. (2002) *Historical research. A guide*. London: Pearson Education.

McGaffin, C.G. (1910) An anatomical analysis of seventy cases of senile dementia. *American Journal of Insanity*, 65:649-656.

McGeer, P.L., Itagaki, S., Tago, H. and McGeer, E.G. (1987) Reactive microglia in patients with senile dementia of the Alzheimer type are positive for the histocompatibility glycoprotein HLA-DR. *Neuroscience Letters*, 79(1-2):195-200.

McHugh, P.R. and Folstein, M.F. (1973) Address to the American academy of neurology, recent advances in dementia (unpubl.) Cited in: McHugh, P.R. and Folstein, M.F. (1975) Psychiatric symptoms of Huntington's chorea – a clinical and phenomenologic study. In: Benson, D.F. and Blumer, D. (eds.) *Psychiatric aspects of neurologic disease.* New York: Grune and Straton, pp.267-286.

McCay, C.M., Pope, E., Lunsford, W., Sperling, G. and Sambhavaphol, P. (1957) Parabiosis between old and young rats. *Gerontologia*, 1(1):7-17.

McKay, E. and Counts, S.E. (2017) Multi-infarct dementia: a historical perspective. *Dementia and Geriatric Cognitive Disorders Extra,* 7:160-171.

McKeown, T. (1976) *The modern rise of population.* New York: Academic Press.

McKhann, G.M. (2011) Changing concepts of Alzheimer disease. *The Journal of the American Medical Association,* 305(23):2458-2459.

McKhann, G.M., Knopman, D.S., Chertlow, H., Hyman, B.T., Jack, C.R.Jr., Kawas, C.H., Klunk, W.E., Koroshetz, W.J., Mandy, J.J., Mayeux, R., Mohs, J.C., Rossor, M.N., Scheltens, P., Carrillo, M.C., Thies, B., Weintraub, S. and Phelps, C.H. (2011) The diagnosis of dementia due to Alzheimer's disease: recommendations from the National Institute on Aging – Alzheimer's association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimer's and Dementia,* 7(3):263-269.

McKhann, G., Drachman, D., Folstein, M., Katzman, R., Price, D., Stadlam, E.M. (1984) Clinical diagnosis of Alzheimer's disease. Report of the NINCDS-ADRDA work group under the auspices of the Department of Health and human services task force on Alzheimer's disease. *Neurology,* 34:939-944.

McKusick, V.A. (1966) Mendelian inheritance in man. Baltimore: John Hopkins University Press.

McMeneney, W.H. (1963) Alzheimer's disease: problems concerning its concept and nature. *Acta Neurologica Scandinavica*, 39:369-380.

Medical Research Council (1977) Senile and presenile dementia: A report of the MRC subcommittee. Compiled by Lishman, W.A. London: MRC

Medina, R. (2014) From the medicalisation of dementia to the politics of memory and identity in three Spanish documentary films: Bicicleta, cullera, poma, Las voces de la memoria and Bucarest: la memòria perduda. *Aging and Society,* 34:1688-1710.

Meng, X. and D'Arcy, C. (2012) Education and dementia in the context of the cognitive reserve hypostudy: a systematic review with meta-analysis and qualitative analyses. *PLoS ONE,* 7(6):e38268.

Mental Health Foundation (2015) *Dementia, rights, and the social model of disability: A new direction for policy and practice?* London: Mental Health Foundation.

Mercier, C. (1895) *Sanity and insanity.* London: Walter Scott.

Mersky, H., Ball, M.J., Blume, W.T., Fox, A.J., Fox, H., Hersch, E.L., Kral, V.A. and Palmer, R.B. (1980) Relationships between psychological measurements and cerebral organic changes in Alzheimer's disease. *Canadian Journal of Neurological Sciences*, 7:45-49.

Merton, R.K. and Lazarsfield, P.F. (1943) Studies in radio and film propaganda. *Transactions,* 2(6):58-79.

Meynert, T. (1885) *Psychiatry: A clinical treatise on diseases on the forebrain based on its structure, function and nutrition.* (trans. Sachs, B.) New York: Putman and Sons.

Micale, M.S. and Porter, R. (1994) *Discovering the history of psychiatry*. Oxford: Oxford University Press.

Mielke, M.M., Montine, T. and Khachauturian, A.S. (2012) Vascular diseases: one pathway toward new conceptual models of dementia. *Alzheimer's and Dementia,* 8(Suppl. 5, issue 5):S60-S70.

Minati, L., Edginton, T., Bruzzone, M.G. and Giaccone, G. (2009) Current concepts in Alzheimer's disease: a multidisciplinary review. *American Journal of Alzheimer's Disease and Other Dementias,* 24(2):95-121.

Mingazzini, G. (1913) On aphasia due to atrophy of the cerebral convolutions. *Brain,* 36:493-524.

Mitchell, S.L., Teno, J.M., Kiely, D.K., Haffer, M.L., Jones, R.N., Prigerson, H.G., Volicer, L., Givens, J.L. and Hamel, M.B. (2009) The clinical course of advanced dementia. *New England Journal of Medicine,* 361(16):1529-1538.

Möller, H.J. and Graeber, M.B. (1998) The case described by Alois Alzheimer in 1911: historical and conceptual perceptions based on the clinical record and neurohistological sections. *European Archives of Psychiatry and Clinical Neurosciences,* 248:111-122.

Möller, H.J. and Graeber, M.B. (2000) Johann F: The historical relevance of the case for the concept of Alzheimer disease. In: Whitehouse, P.J., Maurer, K. and Ballenger, J.F. (eds.) *Concepts of Alzheimer Disease. Biological, Clinical and Cultural Perspectives.* London: The John Hopkins University Press, pp.30-46.

Molloy, D.W., Alemayehu, E. and Roberts, R. (1991) Reliability of a standardized mini-mental state examination compared with the traditional mini-mental state examination. *American Journal of Psychiatry,* 148:102-105.

Moore, S., Sandman, C.A., McGrady, K. and Kesslak, J.P. (2001) Memory training improves cognitive ability in patients with dementia. *Neuropsychol Rehabilitation,* 11:245-261.

Moorhouse, P. and Hamilton, L.M. (2014) Not if, but when: Impact of a driving and dementia awareness and education campaign for primary care physicians. *Canadian Geriatrics Journal,* 17:70-75.

Moran, M., Lynch, C.A., Walsh, C., Coen, R., Coakley, D. and Lawlor, B.A. (2005) Sleep disturbance in mild to moderate Alzheimer's disease. *Sleep Medicine*, 6(4):347-352.

Moreira, T. and Palladino, P. (2009) Ageing between gerontology and biomedicine. *BioSocieties*, 4(4):349-365.

Morris, M.C., Tangney, C.C., Wang, Y., Sacks, F.M., Bennett, D.A. and Aggarwal, N.T. (2105) MIND diet associated with reduced incidence of Alzheimer's disease. *Alzheimer's and Dementia*, 11(9):1007-1014.

Morris, N. and Rothman, D.J. (1998) *The Oxford history of the prison. The practice of punishment in Western society.* Oxford: Oxford University Press.

Morrison, A. (1839) The physiognomy of mental diseases. (2nd ed.) London: British Library facsimile.

Mortimer, J.A., Schuman, L. and French, L. (1981) Epidemiology of dementing illness. In: Mortimer, J.A. and Schuman, L.M. (eds.) *The epidemiology of dementia: monographs in epidemiology and biostatistics.* New York: Oxford University press, pp. 323-333.

Morton, I. (1999) Person-centred approaches to dementia care. Bicester: Speechmark Publishing Limited.

Mueller, C., Ballard, C., Corbett, A. and Aarsland, D. (2017) Historical landmarks in dementia with Lewy bodies, *The Lancet: Neurology,* 16:348.

Mundt, J.C., Freed, D.M. and Griest, J.H. (2000) Lay person-based screening for early detection of Alzheimer's disease; development and validation of an instrument. *Journal of Gerontology,* 55B:163-170.

Musello, C. (1979) Family photography. In: Wagner, J. (ed.) *Images of information: still photography in the social sciences*. Beverly Hills Ca: Sage, pp.101-118.

Naroll, R. (1962) *Data quality control.* New York: Free Press.

Nascher, I. (1911) Senile Mentality. *International Clinics,* 4:48-59.

Nascher, I.L. (1915) Evidences of senile impairment. *American Journal of clinical medicine,* 22:544 – 449.

Nascher, I.L. (1914) *Geriatrics: The diseases of old age and their treatment.* Reprinted as a facsimile. Reprint. New York: Amp Press.

National Audit Office (2007) *Improving Services and Support for People with Dementia*. London: TSO.

National Institute for Health and Clinical Excellence and Social Care Institute for Excellence (2006) *Dementia: Supporting People with Dementia and their Carers in Health and Social Care.* London: Clinical Guidelines.

Naville, F. (1922) Etudes sur les complications et les sequelles mentales de l'encephalite epidemique; La bradyphrenie. *L'Encephale,* 17:369-375.

Nedergaard, M. (2013) Garbage truck of the brain. *Science,* 340(6140):1529-1530.

Nelson, L. and Tablet, N. (2015) Slowing the progression of Alzheimer's disease: what works? *Ageing Research Reviews*, 23, Pt B:193-209.

Nettleton, S. (1992) *Power, pain and dentistry.* Buckingham: Open University Press.

Neuman, M.A. and Cohen, R. (1967) Progressive subcortical gliosis – a rare form of presenile dementia. *Brian,* 90:405-418.

Neuropathology Group of the Medical Research Council Function and Aging Study (MR CFAS) (2010) Pathological correlates of late-onset dementia in

multi-centre community-based population in England and Wales. *Lancet,* 357: 169-175.

Newton, R.D. (1948) The identity of Alzheimer's disease and senile dementia and their relationship to senility. *British Journal of Psychiatry,* 94(395):225-249.

Niedermeyer, E. and Ghigo, J.O. (2011) Alzheimer dementia: an overview and a promising new concept. *American Journal of Electroneurodiagnostic Technology,* 51:82-91.

Nielsen-Brown, N. and Chui, H.C. (2009) Vascular dementia. In: Charney, D. and Nestler, E. (eds.), *Neurobiology of mental illness.* (3rd ed.) Oxford: Oxford University Press.

O'Donnell, W.E. (2001) The neuropsychological impairment scale – senior procedure for evaluating awareness disturbance in geriatric patients. *Journal of Clinical Psychology,* 57:423-427.

Ohry, A. and Buda, O. (2015) Teofil Simchowicz (1879-1957): the scientist who coined senile plaques in neuropathology. *Romanian Journal of Morphology and Embryology,* 56(4):1545-1548.

Oliver, M. (1983) *Social work with disabled people.* Basingstoke: Palgrave Macmillan.

Oliver, M. (2004) The social model in action: if I had a hammer. In: Barnes, C. and Mercer, G. (eds.) *Implementing the social model of disability: theory and research.* Leeds: The Disability Press.

Osler, W. (1905) Valedictory address at John Hopkins university. *Journal of the Medical Association*, 44:705-710.

Osler, W. and McCrae, T. (1921) *The principles and practice of medicine*. (9th ed.) New York: Appleton.

Papavramidou, N. (2018) The ancient history of dementia. *Neurological Sciences,* 39:2011-2016.

Papez, J.F. (1970) Theodor Meynert. In: Haymaker, W. and Schiller, F. (eds.) *The Founders of Neurology*. Springfield Ill: Charles C Thomas.

Paquette, M., Bull, M., Wilson, S. and Dreyfus, A. (2010) A complex elder care simulation using improvisational actors. *Nurse Educator,* 35(6):254-258.

Parker, I. (1992) *Discourse dynamics: Critical analysis for social and individual psychology.* London: Routledge.

Pattie, A.H. and Gilleard, C.J. (1979) *Manual of the Clifton Assessment Procedures for the Elderly (CAPE).* Sevenoaks: Hodder and Stoughton Educational.

Perry, E.K., Perry, R.H., Blessed, G. and Tomlinson, B.E. (1977) Necropsy evidence of central cholinergic deficits in senile dementia. *Lancet* i:189.

Perusini, G. (1909) Über klinisch und histologisch eigenartige psychische Erkrankungen des späteren Lebensalters. In: Nissl, F. and Alzheimer, A. (eds.) Histologische und histopathologische Arbeiten. Jena: Verlag G Fischer, pp.297-351.

Perusini, G. (1911) Sul valore nosografico di alcumi reperti histopatologici caratteristici per la senilità. *Rivista Italiana di Neuropatologia, Psichiatria ed Elettroterapia*, 4:145-213.

Philip, M. (1985) Michel Foucault. In: Skinner, Q. (ed.) *The return of grand theory in the human sciences*. Cambridge: Cambridge University Press, pp. 67-81.

Pick, A. (1892) Uber die beziehungen der senilen hirnatrophie zur aphasie. *Prgaer Medicinische Wochenschrift*, 14:403-404.

Pick, A. (1906) Ueber einen weiteren Symptomenkonmplex im Rahmen der Dementia senilis, bedingt durch umschriebene, stärkere Hirnatrophie (gemischte Apraxie). *Fahrbuch der Psychiatrie und Neurologie*, 19:97-108.

Pickett, W. (1903) *Senile dementia; a clinical study of two hundred cases with particular regard to types of the disease.* Transactions of the Philadelphia Neurological Society, April 28 1903.

Pinel, P. (1801) *Traité Médico-Philosophique sur l'Aliénation Mentale, ou la Maine.* Paris: Richard, Caille and Ravier (trans. Davis, D.D. (1962) *A Treatise on Insanity.* New York: Hafner).

Pinel, P. (1816) *Nosografia filosofica o il metedo dell'analisi applicator alla medicina (traduz).* Domenico: Palmero.

Pinel, P. (1818[1798]) *Nosographie philosophique.* (6th ed.) Paris: Boson.

Pinzon, L.C., Claus, M., Perrar, K.M., Zepf, K.I., Letzel, S. and Weber, M. (2013) Dying with dementia: symptom burden, quality of care, and place of death. *Deutsches Arzteblatt International,* 110(12):195-202.

Platt, J. (1981a) Evidence and proof in documentary research: Part I, Some specific problems of documentary research. *Sociological Review,* 29(1):31-52.

Platt, J. (1981b) Evidence and proof in documentary research: Part II, Some shared problems of documentary research. *Sociological Review*, 29(1): 53-66.

Plum, F. (1979) D*ementia: an approaching epidemic. Nature,* 279:372-373.

Plummer, K. (1981) *The making of the modern homosexual*. London: Hutchinson.

Plummer, K. (1995) The modernisation of gay and lesbian stories. In: Plummer, K. (ed.) *Telling Sexual Stories*. London: Routledge, pp.81-96.

Pollen, D.A. (1996) *Hannah's heirs: The quest for the genetic origins of Alzheimer disease.* New York: Oxford University Press.

Pollen, D.A. (2000) The history of the genetics of Alzheimer disease. In: Whitehouse, P.J., Maurer, K. and Ballenger, J.F. (eds.) *Concepts of Alzheimer disease. Biological, clinical and cultural perspectives.* London: The John Hopkins University Press, pp. 115-124.

Popper, K. (1962) *The open society and its enemies.* London: Routledge and Kegan Paul.

Portacolone, E., Berridge, C., Johnson, J. and Schicktanz, S. (2014) Time to reinvent the science of dementia: the need for care and social integration. *Aging and Mental Health,* 18(3): 269-275.

Porter, R. (1995) Dementia. In: Berrios, G. and Porter, R. (eds.) *A history of clinical psychiatry. The origin and history of psychiatric disorders*. London: The Athlone Press, pp.52-62.

Porter, R. (2002) *Madness – a brief history*. Oxford: Oxford University Press.

Post, S.G. (2000) The concept of Alzheimer disease in a hypercognitive society. In: Whitehouse, P.J., Maurer, K. and Ballenger, J.F. (eds.) *Concepts of Alzheimer disease. Biological, clinical and cultural perspectives.* London: The John Hopkins University Press, pp. 245-256.

Potter, J. and Wetherell, M. (1987) *Discourse and Social Psychology. Beyond attitudes and behaviour*. London: Sage.

Powell, J.L. and Biggs, S. (2003) Foucauldian gerontology: a methodology for understanding ageing. *Electronic Journal of Sociology,* ISSN 1198 3655.

Prichard, J.C. (1837) *A treatise on insanity and other disorders affecting the mind.* Philadelphia: Haswell, Barrinton, and Haswell.

Prince, M., Knapp, M., Guerchet, M., McCrone, P., Prina, M., Comas-Herrera, A., Wittenberg, R., Adelaja, B., Hu, B., King, D., Rehil,l A. and Salimkumar, D, (2014) *Dementia UK: Second edition* – Overview. London: Alzheimer's Society.

Proctor, G. (2001) Listening to older women with dementia. *Disability and Society,* 16(3):361-376.

Pulsford, D., Hope, K., and Thompson, R. (2007) Higher education provision for professionals working with dementia: a scoping exercise. *Nurse Education Today,* 27:5-13.

Qiu, C., Kivipelto, M., and von Strauss, E. (2009) Epidemiology of Alzheimer's disease: occurrence, determinants and strategies toward intervention. *Dialogues in Clinical Neuroscience*, 11(2):111-128.

Ramirez-Bermudez, J. (2012) Alzheimer's disease: critical notes on the history of a medical concept. *Archives of Medical Research,* 43(8):595-599.

Ranke, L. (1852) *Civil Wars and Monarchy in France, in the Sixteenth and Seventeenth Centuries*. (trans. Garvey, M.A.). London: Richard Bentley.

Ranke, L. (1943) *The Ottoman and the Spanish Empires, in the Sixteenth and Seventeenth Centuries.* (trans. Kelly, W.K.) London: Whittaker and Co.

Rapley, T. (2007) *Doing conversation, discourse and document analysis*. London: Sage Publications.

Rebeiz, J., Kolodney, E. and Richardson, E. (1968) Corticodentatonigral degeneration with neuronal achromatasia. *Archives of Neurology,* 18:20-33.

Redlich, E. (1898) Ueber miliare sklerose der hirnrinde bei seniler atrophie. *Jahrbucher für Psychiatrie und Neurologie,* 17:208-216.

Reisberg, B. (2006) Diagnostic criteria in dementia: a comparison of current criteria, research challenges, and implications for DSM-V. *Journal of Geriatric Psychiatry and Neurology,* 19(3):137-146.

Reisberg, B., Ferris, S.H., de Leon, M.J. and Crook, T. (1982) The global deterioration scale (GDS) for the assessment of primary degenerative dementia. *American Journal of Psychiatry,* 139:136-1139.

Reisberg, B., Finkel, S., Overall, J. and Schmidt-Gollas, N. (2001) The Alzheimer's disease activities of daily living international scale (ADL-IS). *International Psychogeriatrics,* 13(2):163-181.

Reitan, R.M. (1958) Validity of the Trail Making Test as an indicator of organic brain damage. *Perceptual and Motor Skills,* 8:271-271.

Richards, M. and Brayne, C. (2010) What do we mean by Alzheimer's disease? *British Medical Journal,* 341:c4670.

Richardson, J.C., Steele, J.C. and Olszewski, J. (1963) Supranuclear opthalmoplegia, pseudobulbar palsy, nuchal dystonia and dementia. *Transactions of the American Neurological Association,* 88:25-27.

Rickert, H. (1962) *Science and History*. Princeton NJ: Van Nostrand.

Ritchie, K., Allard, M., Huppert, F.A., Nargeot, C., Pinek, B. and Ledesert, B. (1993) Computerized cognitive examination of the elderly (ECO). The development of a neuropsychological examination for clinical and population use. *International Journal of Geriatric Psychiatry,* 8:899-914.

Ritchie, J. and Spencer, L. (1994) Qualitative data analysis for applied policy research. In: Bryman, A. and Burgess, R.G. (eds.) *Analysing qualitative data.* London: Routledge, pp. 173-194.

Robakis, N.K., Ramakrishna, N., Wolfe, G. and Wisniewski, H.M. (1987) Molecular cloning and characterisation of a cDNA encoding the cerebrovascular and the neuritic plaque amyloid peptides. *Proceedings of the National Academy of Sciences of the United States of America,* 84(12): 4190-4194.

Robbins, N.M. and Bernat, J.L. (2017) Should dementia be accepted as a disability to help restore hope during cognitive decline? 19(7): 649-655.

Roberts, M.A., Caird, F.L., Grossat, K.W. and Steven, J.L. (1976) Computerized tomography in the diagnosis of cerebral atrophy. *Journal of Neurology, Neurosurgery and Psychiatry*, 39:905-915.

Robertson, A. (1990) The politics of Alzheimer's disease: a case study in apocalyptic demography. *International Journal of Health Sciences,* 20(3):429-442.

Robertson, D., Rockwood, K. and Stolee, P. (1982) A short mental status questionnaire. *Canadian Journal on Ageing,* 1:16-20.

Román, G. (1999) A historical review of the concept of vascular dementia: lessons from the past for the future. *Alzheimer's Disease and Associated Disorders,* 13(Suppl. 3):S4-8.

Román, G. (2003) Vascular dementia: a historical background. *International Psychogeriatrics,* 15(Suppl 1):11-3.

Rosen, W.G., Mohs, R.C. and Davis, K.L. (1984) A new rating scale for Alzheimer's disease. *American Journal of Psychiatry,* 141:1356-1364.

Roses, A.D. (2006) On the discovery of the genetic association of apolipoprotein E genotypes and common late-onset Alzheimer disease. *Journal of Alzheimer's disease*, 9(3): 361-366.

Rosenberg, C.E. (1992a) Framing disease: illness, society, and history. In: Rosenberg, C.E. and Golden, J. (eds.) *Framing diseases: studies in cultural history*. New Brunswick, NJ: Rutgers University Press.

Rosenberg, C.E. (1992b) Explaining epidemics and other studies in the history of medicine. New York: Cambridge University Press.

Rosenberg, C.E. (1992c) *The crisis in psychiatric legitimacy: reflections on psychiatry, medicine and public policy, exploring epidemics and other essays in the history of medicine*. New York: Cambridge University Press.

Roth, M. (1978) Diagnosis of senile and related forms of dementia. *Ageing,* 7:85.

Roth, M. (1994) Dementia and normal ageing of the brain. In: Huppert, F.A., Brayne, C. and O'Connor, D. (eds.) *Dementia and normal ageing.* Cambridge: Cambridge University Press, pp 57-76.

Roth, M. and Hopkins, B. (1953) Psychological test performance in patients over 60. I. Senile Psychosis and the affective disorders of old age. *Journal of Mental Science*, 99:439.

Roth, M., Tomlinson, B.E. and Blessed, G. (1966) Correlation between scores for dementia and counts of 'senile plaques' in cerebral grey matter of elderly subjects. *Nature,* 209(5018):109-110.

Rothschild, D. (1934) Alzheimer's disease: a clinicopathologic study of five cases. *American Journal of Psychiatry,* 91:485-519.

Rothschild, D. (1937) Pathologic changes in senile psychoses and their psychobiologic significance. *American Journal of Psychiatry,* 93:757-787.

Rothschild, D. and Sharp, M.L. (1941) The origin of senile psychoses: neuropathologic factors of a more personal nature. *Diseases of the Nervous System,* 2:49-54.

Rothschild, D. (1956) Discussion of the article senescence, senility and Alzheimer's disease. *American Journal of Psychiatry*, 113:133-137.

Rothschild, D. and Kasanin, J. (1936) Clinicopathologic study of Alzheimer's disease: relationship to senile conditions. *Archives of Neurology and Psychiatry,* 36:293-321.

Rottenberg, D.A. and Hochberg, F.H. (1977) *Neurological cases in modern translation*. New York: Hafner.

Royal College of Psychiatrists (2005) *Who Cares Wins: Improving the outcome for older people admitted to the general hospital. Guidelines for the development of liaison mental health services for older people*. London: RCP

Royal College of Psychiatrists (2011) *National Audit of Dementia Care in General Hospitals.* London: Healthcare Quality Improvement Partnership.

Runes, D.V. (1947) *Selected writings of Benjamin Rush.* New York: Philosophical Press.

Rush, B. (1793) An account of the state of mind and body in old age; with observations on its diseases, and their remedies. Reprinted as 'On Old Age' In:

Runes, D.V. (ed.) *Selected Writings of Benjamin Rush*. New York: Philosophical Press.

Russell, W.L. (1902) Senility and senile dementia. *American Journal of Insanity*, 59:625-633.

Sabat, S. (2001) *The experience of Alzheimer's disease: life through a tangled veil*. Oxford: Blackwell.

Sachdev, P. (2000) Is it time to retire the term 'dementia'? *The Journal of Neuropsychiatry and Clinical Neurosciences* 12(2): 276-279.

Sava, G.M., Wharton, S.B., Ince, P.G., Forster, G., Mathews, F.E. and Brayne, C. (2009) Age, Neuropathology and Dementia. *New England Journal of Medicine*, 360(22):2302-2309.

Sacktor, N. and Robertson, K. (2014) Evolving clinical phenotypes in HIV-associated neurocognitive disorders. *Current Opinion in HIV and AIDS*, 9(6): 517-520.

Sampson, L., Harrison-Dening, K., Greenrush, W., Mandal, U., Holman, A. and Jones, L. (2009) *End of life care for people with dementia.* UCL: Marie Curie Palliative Research Unit.

Sarteschi, U. (1909) Contributo all'istologia pathologica della presbiofrenia. *Riv Sper Freniatr*, 35:464-468.

Satz, P. (1993) Brain reserve capacity on symptom onset after brain injury: a formulation and review of evidence for threshold theory. *Neuropsychology,* 7:273-295.

Saunders, A.M., Strittmatter, W.J., Schemechel, D., George-Hyslop, P.H., Periack-Vance, M.A., Joo, S.H., Rosi, B.L., Gusella, J.F., Crapper-Maclachlon, D.R., Alberts, M.J., Hulette, C., Crain, B. and Goldgaber, D. (1993) Association of apolioprotein E allele epsilon 4 with late-onset familial and sporadic Alzheimer's disease. *Neurology,* 43(8):1467-1472.

Sava, G.M., Wharton, S.B., Ince, P.G., Forster, G., Mathews, F.E. and Brayne, C. (2009) Age, neuropathology and dementia. *New England Journal of Medicine,* 360(22):2302-2309.

Saxton, J., McGonigle-Gibson, K., Swihart, A., Miller, M. and Boller, F. (1990) Assessment of severely impaired patients: description and validation of a new neuropsychological test battery. *Psychological Assessment,* 2:298-303.

Scanlan, J. and Borson, S. (2001) The mini-cog: receiver operating characteristic with expert and naïve raters. *International Journal of Geriatric Psychiatry,* 16: 216-222.

Schenk, D. (2002) Amyloid-ß immunotherapy for Alzheimer's disease: the end of the beginning. *Nature Reviews: Neuroscience,* 3:824-828.

Schneider, C.V. (1672) *Liber de nova gravissimorum trium morborum curatione, de apoplexia, paralysi.* Frankfurt: Bakium.

Schneider, J.A., Arvanitakis, Z., Bang, W. and Bennett, D.A. (2007) Mixed brain pathologies account for most dementia cases in community dwelling older persons. *Neurology,* 69:2197-2204.

Schnitzler, J.G. (1911) Zur Abgrenzung der sogenannten Alzheimerschen Erkranking. Ztschr. *Neurol Psychiatr*., 7:34-37.

Schroeter, M.L., Laird, A.R., Chwiesko, C., Deuschl, C., Schneider, E., Bzdok, B., Eikhoff, S.B. and Neumann, J. (2014) Conceptualizing neuropsychiatric diseases with multimodal data-driven meta-analyses – the case of behavioural variant frontotemporal dementia. *Cortex: A Journal Devoted to the Study of the Nervous System and Behaviour,* 57: 22-37.

Schuler, M.S., Becker, S., Kaspar, R., Nikolaus, T., Kruse, A. and Basler, H.D. (2007) Psychometric properties of the German "pain assessment in advanced dementia scale" (PAINAD-G) in nursing home residents. *Journal of the American Medical Association,* 8(6):388-395.

Schwab, R.N. and Rex, W.E. (1972) Inventory of Diderot's encyclopdédie. *Studies on Voltaire and the Eighteenth Century*, 93:21-22.

Schwartz, M.F. and Stark, J.A. (1992) The distinction between Alzheimer's disease and senile dementia: historical considerations. *Journal of the History of the Neurosciences,* 1(3):169-187.

Scott, J. (1990) *A matter of record, documentary sources in social research*. Cambridge: Polity Press.

Seiter, E. (1992) Semiotics, structuralism and television. In: Allen, C. (ed.) *Channels of discourse, reassembled: television and contemporary critique*. University of North Carolina Press: Chapel Hill, pp.17-41.

Selye, H. (1978) *The stress of life.* New York: McGraw-Hill.

Shader, R.I., Harmaty, J.S. and Salzmann, C. (1974) A new scale for clinical assessment in geriatric populations: Sandoz clinical assessment-geriatric (SCAG). *Journal of the American Geriatrics Society*, 22: 107-113.

Shakespeare, W. (1623) As You Like It, Act 2, Scene 7.

Shaw, L.M., Vandertichele, H., Knapik-Czajka, M., Clark, C.M., Aisen, P.S., Peterson, R.C., Blenow, K., Soares, H., Simon, A., Lewczuk, P., Dean, r., Siemers, e., Potter, w., Lee, V.M.Y. and Trojanowsji, J.Q. (2009) Alzheimer's disease neuroimaging initiative. Cerebrospinal fluid biomarker signature in Alzheimer's disease neuroimaging initiative subjects. *Annals of Neurology,* 65(4): 403-413.

Sheppard, E. (1873) *Lectures on madness in its medical, legal and social aspects*. London: J. Churchill, A. Churchill.

Shih-Yin, L. and Lewis, F.N. (2015) Dementia friendly, dementia capable and dementia positive: concepts to prepare for the future. *Gerontologist,* 55(2): 237-244.

Shorter, E. (1997) *A history of psychiatry - from the era of the asylum to the age of Prozac*. New York: John Wiley and Sons.

Shua-Haim, J.R. (1998) Alzheimer's syndrome and not Alzheimer's disease: the historical struggle to define the disease. *American Journal of Alzheimer's Disease,* 13(2):92-95.

Shulman, K., Shedletsky, R. and Silver, I. (1986) The challenge of time. Clock drawing and cognitive function in the elderly. *International Journal of Geriatric Psychiatry,* 1:135-140.

Signoret, J.L. and Hauw, J.J. (1991) *Maladie d 'Alzheimer et autres démences*. Paris: Flammarion.

Silver, A.H. (1956) *Where Judaism Differs.* New York: Macmillan.

Simard, J. (2013) *The End-of-Life Namaste Care Programme for People with Dementia*. (2nd ed.) Baltimore Health Professional Press.

Simchowicz, T. (1911) Histologische studien über die senile demenz. In: Nissl, F. and Alzheimer, A. (eds.). Histologische und histopathologische arbeiten über die grosshirnrinde mit besonderer berücksichtigung der pathologischen anatomie der geistekrankheiten. Jena: Fischer Verlag, 4:267-444.

Simchowicz, T. (1924) Sur la signification des plaques senile et sur la formule senile de l'écorce cérèbrale. *Rev. Neurol.,* 31(Pt 1):221-227.

Simpson, P.M., Surmon, D.J., Wesnes, K.A. and Wilcock, G.K. (1991) the cognitive drug research computerized assessment system for demented patients: a validation study. *International Journal of Geriatric Psychiatry,* 6: 95-102.

Sjögren, T. (1950) Hereditary congenital spinocerebellar ataxia accompanied by congenital cataract and oligophrenia. *Confinia Neurologica,* 10:293-308.

Skills for Care/Skills for Health (2011) *Common Core Principles for Supporting People with Dementia*. Leeds. Available from www.skillsforcare.org.uk and www.skillsforhealth.org.uk [accessed 12/3/13].

Slater, D. (1998) Analysing cultural objects: content analysis and semiotics. In: Slater, D. (ed.) *Researching Society and Culture*. London: Sage, pp.233-244.

Smart, B. (1985) *Michel Foucault*. Chichester: Ellis Horwood and Tavistock.

Smith, E. (1930 [2000 BCE]) *The Edwin Smith Surgical Papyrus*. (Trans. by Breasted, J.). Chicago: University of Chicago Press.

Smith, D. (2014) The return of historical sociology. *The Sociological Review,* 62: 206-216.

Smythe, A., Jenkins, C., Harries, M., Atkins, S., Miller, J., Wight, J. and Oyebode, J. (2014) Evaluation of dementia training for staff in acute hospital settings. *Older People,* 26(2): 18-24.

Snowdon, D. (1997) Ageing and Alzheimer disease: lessons from the nun study. *The Gerontologist*, 35:150-156.

Solomon, P.R., Hirschoff, A., Kelly, B., Relin, M., Brush, M., De Veaux, R.D. and Pendlebury, W.W. (1998) A 7 minute neurocognitive screening battery highly sensitive to Alzheimer's disease. *Archives of Neurology,* 55(3):349-355.

Southard, E.E. (1910) Anatomical findings in senile dementia: a diagnostic study bearing especially on the group of cerebral atrophies. *American Journal of Insanity*, 66:571-577.

Spearman, C. (1904) General intelligence objectively determined and measured. *American Journal of Psychology*, 15:201-293.

Spearman, C. (1927) *The abilities of man*. New York: MacMillan.

Sperling, R.A., Aisen, P.S., Beckett, L.A., Bennett, D.A., Craft, S., Fagan, A.M., Iwatsubo, T., Jack Jr, C.R., Kaye, J., Montine, T.J., Park, D.C., Reiman, E.M., Rowe, C.C., Siemers, E., Stern, Y., Yaffe, K., Carrillo, M.C., Thies, B., Morrison-

Bogard, M., Wagster, M.V. and Phelps, C.H. (2011) Towards defining the preclinical stages of Alzheimer's disease: recommendations from the National Institute on Aging – Alzheimer's Association workshops on diagnostic guidelines for Alzheimer's disease. *Alzheimer's and Dementia,* 7(3):280-292.

Stamps, J.J., Bartoshuk, L.M. and Heilman, K.M. (2013) A brief olfactory test for Alzheimer's disease. *Journal of the Neurological Sciences,* 333(1-1):19-24.

Steadman, J.G. (1976) From historical sociology to theoretic history. *British Journal of Sociology,* xxvii:295-305.

Stephan, B. and Brayne, C. (2010) Prevalence and projections of dementia. In: Downs, M. and Bowers, B. (eds.) Excellence in dementia care. Research into practice. Berkshire: Open University Press, pp. 9-34.

Stern, K. (1939) Severe dementia associated with bilateral symmetrical degeneration of the thalamus. *Brain,* 62:157-171.

Stokes, G. (2003) *Challenging behaviour in dementia: a person-centred approach*. Bicester: Speechmark Publishing.

Strittmatter, W.J., Saunders, A.M., Scmechel, D., Pericak-Vance, M., Enghild, J., Salvesen, G.S. and Roses, A.D. (1993) Apolipoprotein E: high-avidity binding to ß-amyloid and increased frequency of type 4 allele in late-onset familial Alzheimer disease. *Proceedings of the National Academy of Sciences of the United States of America*, 90(5):1977-1981.

Sturgis, P. (2008) Designing samples. In: Gilbert, N. (ed.) *Researching social life*. 3rd ed. London: Sage Publications, pp.165-181.

Summers, W.K., Majovski, L.V., Marsh, G.M., Tachiki, K. and Kling, A. (1986) Oral tetrahydroaminoacridine in long-term treatment of senile dementia, Alzheimer's type. *New England Journal of Medicine,* 315(20):1241-1245.

Semmers, W.K., Viesselman, J.O., Marsh, G.M. and Candelora, K. (1981) Use of THA in treatment of Alzheimer's-like dementia: pilot study in twelve patients. *Biological Psychiatry,* 16(2):145-153.

Sunderland, T., Hill JL, Mellow, A.M., Lawlor, B.A., Gundersheimer, J., Newhouse, P.A. and Grafman, J.H. (1989) Clock drawing in Alzheimer's disease. *Journal of the American Geriatrics Society,* 37:725-729.

Surr, C., Smith, S., Crossland, J. and Robins, J. (2016) Impact of a person-centred dementia care training programme on hospital staff attitudes, role efficacy and perceptions of caring for people with dementia: a repeated measures study. *International Journal of Nursing Studies,* 53: 144-15.

Sweeney, J.F. (2005) Historical research: examining documentary sources. *Nurse Researcher,* 12(3):61-73.

Takahasi, K., Tanabe, K., Ohnuki, M., Narita, M., Ichisaka, T., Tomoda, K. and Yamanaka, S. (2007) Induction of pluripotent stem cells from adult human fibroblasts be defined factors. Cell, 131(5):861-872.

Takahasi, K. and Yamanaka, S. (2006) Induction of pluripotent stem cells from mouse embryonic and adult fibroblast cultures by defined factors. Cell, 126(4):663-676.

Tanzi, R.E. (2013) A brief history of Alzheimer's disease gene discovery. *Journal of Alzheimer's Disease,* 33(Suppl. 1)S5-13.

Tanzi, R.E., Gusella, J., Watkins, P.C., Bruns, G.A., St George-Hyslop, P., Van Keuren, M.L., Patterson, D., Pagan, S., Kurnit, D.M. and Neve, R.L. (1987) Amyloid beta protein gene: cDNA, mRNA distribution, and genetic linkage near the Alzheimer locus. *Science,* 235(4791): 880-884.

Tapiola, T., Alafuzoff, I., Herukka S-K., Parkkinen, L., Hartikainen, P., Soinlnen, H. and Pirttilä, T. (2009) Cerebrospinal fluid β-amyloid 42 and tau proteins as biomarkers of Alzheimer-type pathologic changes in the brain. *Archives of Neurology,* 66(3):382-389.

Teipel, S.J., Ewers, M., Wolf, S., Jessen, F., Kölsch, H., Arlt, S., Luckhaus, C., Schōnknecht, P., Schmidtke, K., Heuser, I., Frölich, L., Ende, G., Pantel, J., Wiltfang, J., Rakebrandt, F., Peters, O., Bom, C., Kornhuber, J. and Hampel, H.

(2010) Multicentrre variability of MRI-based medial temporal lobe volumetry in Alzheimer's disease. *Psychiatry Research: Neuroimaging,* 182(3):244-250.

Teng, E.L. and Chui, H.C. (1987) The modified mini mental state (3MS) examination. *Journal of Clinical Psychiatry,* 48: 314-318.

Teng, E.L., Hasegawa, K., Homma, A., Imai, Y., Larson, E., Graves, A., Sugimoto, K., Yamaguchi, T., Sasaki, H., Chiu, D. and White, L.R. (1994) The Cognitive Abilities Screening Instrument (CASI): a practical test for cross-cultural epidemiological studies of dementia. *International Psychogeriatrics,* 6(1):45-58.

Terry, R.D., Fitzgerald, C., Peck, A., Milner, J. and Farmer, P. *(*1977) Cortical cell counts in senile dementia. *Journal of Neuropathology and Experimental Neurology*, 36(3):633.

Terry, R.D., Gonatas, N.K. and Weiss, M. (1964) Ultrastructural studies in Alzheimer's presenile dementia. *American Journal of Pathology,* 44:269-297.

The Scottish Government (2010) *Scotland's National Dementia Strategy.* Edinburgh: The Scottish Government.

Thomas, C. (2010) Medical sociology and disability theory. In: Scambler, G. and Scamber, G. (eds.) *New Directions in the Sociology of Chronic and Disabling Conditions: assaults of the life world*. Basingstoke: Palgrave Macmillan, pp.37-56.

Thomas, C. and Milligan, C. (2015) *How can and should UK society adjust to dementia?* York: Joseph Rowntree Foundation.

Thomson, J.A., Itskovitz-Elder, J., Shapiro, S.S., Waknitz, M.A., Swiergiel, J.J., Marshall, V.S. and Jones, J.M. (1998) Embryonic stem cell lines derived from human blastocysts. *Science*, 282(5391):1145-1147.

Thuathail, N. and Welford, C. (2011) Pain assessment tools for older people with cognitive impairment. *Nursing Standard,* 26(6):39-46.

Tomlinson, B.F., Blessed, G. and Roth, M. (1968) Observations on the brains of non-demented old people. *Journal of the Neurological Sciences,* 7:331-356.

Torack, R.M. (1978) *The pathologic physiology of dementia, with indications for diagnosis and treatment*. Berlin: Springer-Verlag.

Torack, R.M. (1979) Adult dementia: history, biopsy, pathology. *Neurosurgery,* 4:432-434.

Torack, R.M. (1983) The early history of senile dementia. In: Reisberg, B. (ed.) *Alzheimer's disease.* New York: The Free Press, pp. 23-28.

Tosh, J. (1991) *The Pursuit of History*. (2nd ed.) London: Pearson Education.

Tosh, J. (2010) *The Pursuit of History*. (5th ed.) Harlow: Pearson Education.

Tsolaki, M, Papaliagkas, V., Anogianakis, G., Bernabei, R., Emre, M., Frolich, L., Visser, P.J., Michel, J-P., Pirttila, T., Olde Rikkert, M., Soininen, H., Sobow, T., Vellas, B., Verhey, F. and Winbald, B. (2010) Consensus statement on dementia education and training in Europe. *The Journal of Nutrition, Health and Ageing,* 14(2):131-135.

Tuchman, G., Daniels, A.K. and Benet, J. (1978) *Hearth and home: images of women in the mass media*. New York: Oxford University Press.

Tuke, W. (1857) *Laws of health*. Boston: John P. Jewett.

Tullo, E. and Allan, L. (2011) What should we be teaching medical students about dementia? *International Psychogeriatrics,* 23(7):1044-1050.

Turner, M.S., Moran, N.F. and Kopelman, M.D. (2002) Subcortical dementia. *British journal of Psychiatry*, 180:148-151.

Union of the Physically Impaired Against Segregation (UPIAS) (1976) *Fundamental principles of disability*. London: UPIAS.

U'Ren, R. (1987) Introduction. In: Pitt, B. (ed.) *Dementia*. London: Churchill Livingstone, pp.1-18.

Varghese, P.B., Castellano, J.M. and Holtzmann, D.M. (2011) Roles of apolipoprotein E in Alzheimer's disease and other neurological disorders. *Lancet Neurology,* 10(3): 241-252.

Vannoy, J.F. and Greene, J.A. (1989) Alzheimer's disease: a brief history. *Journal of the Tennessee Medical Association,* 82(1):15-17.

Villeda, S.A., Luo, J., Mosher, K.I., Zou, B., Britschgi, M., Bieri, G., Stan, T., Fainberg, N., Ding, Z., Eggel, a., Lucin, K.M., Czirr, E., Park, J-S., Couillard-Després, S., Aigner, L., Li, G., Peskind, E.R., Kaye, J.R., Quinn, J.F., Galasko, D.R., Xie, X.S., Rando, T.A. and Wyss-Coray, T. (2011) The ageing systemic milieu negatively regulates neurogenesis and cognitive function. *Nature*, 477(7362):90-94.

Villeda, S.A., Plambeck, K.E., Middeldrop, J., Castellano, J.M., Mosher, K.I., Luo, J., Smith, L.K., Bieri, G., Lin, K., Berdnik, D., Wabl, R., Udeochu, J., Wheatley, E,G., Zou, B., Simmons, D.A., Xio, X.S., Longo, F.M. and Wyss-Coray, T. (2014) Young blood reverses age-related impairments in cognitive functioning and synaptic plasticity in mice. *Nature Medicine,* 20(6):659-663.

Vincent, J.A. (1999) *Politics, power and old age*. Buckingham: Oxford University Press.

Vinters, H.V. (2015) Emerging concepts in Alzheimer's disease. *Annual Review of Pathology: Mechanisms of Disease,* 10(1):291-319.

Virchow, R. (1858) Die celulapathologie in ihrer Bergündung auf physiologische und pathologische Gewebelehre. Berlin: Verlag von August Hirschwald.

Volicer, L. (1986) Need for hospice approach to treatment of patients with advanced progressive dementia. *Journal of the American Geriatrics Society*, 34:655-658.

Volicer, L., et al., Rheaume, Y., Brown, J., Fabiszewski, K.J. and Brady, R.J. (1986) Hospice approach to the treatment of patients with advanced dementia of the Alzheimer type. *Journal of the Medical Association,* 256:2210-2213.

Volicer, L. and Hurley, A. (2015) *Assessment Scales for Advanced dementia*. Baltimore: HPP.

von Haller, A. (1763) *Elementa physiologiae corporis humani*. Lib XVII, sec I. Vol 5. Lusanne.

Von Stockert, F.G. (1932) Subcorticale Demenz. *Archiv für Psychiatrie*, 97:77-100.

Wallerstein, I. (1998 [1996]) Conférence de prestige sur le theme, “Temps et Durée,” Université Libre de Bruxelles, Sept. 2, 1996. In: *Study Eleven*, No. 54, Aug. 1998.

Wallin, A., Gottfries, C-G., Karlsson, I., Regland, B. and Sjogren, M. (1996) Stepwise comparative status analysis (STEP): a tool for identification of regional brain syndromes in dementia. *Journal of Geriatric Psychiatry and Neurology,* 9:185-199.

Walton, J.N. (1977) *Brain’s diseases of the nervous system*. New York: Oxford University Press.

Warren, J.D., Rohrer, J.D. and Rossor, M.N. (2013) Clinical review: frontotemporal dementia. *British Medical Journal*, 347:f4827.

Watermeyer, R. (2012) “From engagement to impact?” Articulating the public value of academic research. *Tertiary Education and Management,* 18(2):115-130.

Watermeyer, R. and Hedgecoe, A. (2016) Selling ‘impact’ peer review projections of what is needed and what counts in REF impact case studies: a retrospective analysis. *Journal of Education Policy,* 31(5):651-665.

Waugh, A., Marland, G., Henderson, J., Robertson, J. and Wilson, A. (2011) Improving care of people with dementia in hospital. *Nursing Standard,* 25(32):44-49.

Webb, S. and Webb, B. (1975 [1932]) *Methods of social study*. Cambridge: Cambridge University Press.

Weber, M, (1930) *The protestant ethic and the spirit of capitalism* (Trans. Parsons, T.), London: George Allen and Unwin.

Weingarten, M.D., Lockwood, A.H., Wwo, S.Y. and Kirschner, M.W. (1975) A protein factor essential for microtubule assembly. *Proceedings of the Natural Academy of Sciences*, 72:1858-1862.

Welsh Government (2011) *National dementia vision for Wales*. Cardiff: Welsh Government.

Wernicke, C. (1874) *The aphasia symptom complex; a psychological study on an anatomical basis*. Reprinted in Eggert GH (ed. and trans.), 1977, Wernicke's works on aphasia. The Hague: Mouton.

Wernicke, C. (1881) *Lehrbuch der Gehirnkrankheiten (Vol. II).* Kassel: Fischer

While, C., Nunn, R., Donohue, L. and Koch, S. (2010) Supporting practice in dementia care: evaluation of an educational programme for district nurses. *Journal of Mental Health Training, Education and Practice,* 5(3):14-21.

White Williams, B., Mack, W. and Henderson, V.W. (1989) Boston naming test in Alzheimer's disease. *Neuropsychologia,* 27:1073-1079.

Whitehouse, P.J. (1997) The genesis of Alzheimer's disease. *Neurology* 48(Suppl. 7):1-6.

Whitehouse, P.J. (2000) History and the future of Alzheimer disease. In: Whitehouse, P.J., Maurer, K. and Ballenger, J.F. (eds.) *Concepts of Alzheimer Disease. Biological, Clinical and Cultural Perspectives.* London: The John Hopkins University Press, pp. 291-305.

Whitehouse, P.J. and George, D. (2008) *The myth of Alzheimer's: what you aren't being told about today's most dreaded diagnosis*. New York: St Martin's.

Whitehouse, P.J. and Post, S.G. (1998) Pharmacogenetics. In: Post, S.G. and Whitehouse, P.J. (eds.) *Genetic testing for Alzheimer's disease: Ethical and clinical issues*. Baltimore: John Hopkins University Press.

Whitehouse, P.J., Maurer, K. and Ballenger, J.F. (2000) *The concepts of Alzheimer disease – biological, clinical and cultural perspectives*. New York: The John Hopkins University Press.

Wilkins, R.H. and Brody, I.A. (1969) Alzheimer's disease. *Archives of Neurology*, 21:109-111.

Wilkinson, C. (2019) Evidencing impact: a case study of UK academic perspectives on evidencing research impact. *Studies in Higher Education,* 44 (1):72-85

Wilkinson, H. (2002) *The perspectives of people with dementia: research methods and motivations*. London: Jessica Kingsley.

Williams, M.M., Storandt, M., Roe, C.M., and Morris, J.C. (2013) Progression of Alzheimer's disease as measured by Clinical Dementia Rating Sum of Boxes scores. *Alzheimer's and Dementia,* 9(Suppl.1):S39-S44.

Williamson, J. (1978) Decoding advertisements. London: Marion Boyars.

Willis, T. (1672) *De anima brutorum quae hominis vitalis ac sensitiva est*. London: Davis.

Willis, T. (1684) *Practice of physick.* (trans. Pordage, S.) London: T. Dring, C. Harper and J. Leigh.

Wilson, R.S., Arnold, S.E., Schneider, J.A., Kelly, J.E., Tang, Y. and Bennett, D.A. (2006) Chronic psychological distress and risk of Alzheimer's disease in old age. *Neuroepidemiology,* 27(3):143-153.

Wilson, R.S., Barnes, L., Bennett, D.A., Li, Y., Bienias, J.L., Mendes de Leon, C.F. and Evans, D.A. (2005) Proneness to psychological distress and risk of Alzheimer disease in a biracial community. *Neurology,* 64(2):380-382.

Wilson, S.A.K. (1912) Progressive lenticular degeneration: a familial nervous disease associated with cirrhosis of the liver. *Brain,* 34:295-309.

Winslow, F. (1854) *Lettsomiam lectures in insanity*. London: John Churchill.

Wolf-Klein, G., Pekmezaris, R., Chin, L., and Weiner, J. (2007) Conceptualising Alzheimer's disease as a terminal medical illness. *American Journal of Hospice and Palliative Medicine,* 24(1):77-82.

Wolf-Klein, G.P., Silverstone, F.A., Levy, A.P., Brod, M.S., and Breuer, J. (1989) Screening for Alzheimer's disease by clock drawing. *Journal of the American Geriatrics Society,* 37:730-734.

Woll, A. (2016) Is aging the new disease? *International Conferences on Advances in Computer-Human Interactions,* 2016: 20-28.

Wood, G.B. (1855) *A treatise on the practice of medicine*. Philadelphia: Lippincott.

World Health Organisation (1949) *Manual of the international statistical classification of diseases, injuries and causes of death (ICD-6).* Geneva: WHO.

World Health Organisation (1967) *Manual of the international statistical classification of diseases, injuries and causes of death (ICD-8).* Geneva: WHO.

World Health Organisation (1974) *Glossary of mental disorders and guide to their classification, for use in conjunction with the international classification of diseases, 8th revision*. Geneva: WHO.

World Health Organisation (1978) *Mental disorders: glossary and guide to their classification in accordance with the ninth revision of the international classification of diseases*. Geneva: WHO.

World Health Organisation (1992) *The ICD-10 Classification of Mental and Behavioural Disorders. Clinical descriptions and diagnostic guidelines*. (10th ed.) Geneva: WHO.

World Health Organisation (1994) *Lexicon of psychiatric and mental health terms*. Geneva: WHO.

World Health Organisation (1997) *Multiaxial classification of the ICD-10 for use in adult psychiatry*. Geneva: WHO.

World Health Organisation (2001) *International classification of functioning, disability and health*. Geneva: WHO.

World Health Organisation (2003) *International classification of primary care, second edition (ICPC-2).* Geneva: WHO.

World Health Organisation (2012) *Dementia: A public health priority*. Geneva: WHO.

Yaffe, K.D., Vittlinghoff, E., Lindquist, K., Barnes, D., Covinsky, K.E., Neylan, T., Kluse, M. and Marmar, C. (2010) Post-traumatic stress disorder and risk of dementia among U.S. veterans. *Archives of General Psychiatry,* 67(6):608-613.

Yates, S. (2015) Truth, power and ethics in care services for people with learning difficulties. In: Tremain, S. (ed.) *Foucault and the Government of disability.* (2nd ed.) Michigan: University of Michigan Press.

Yates, S. and Hiles, D. (2010) Towards a "critical ontology of ourselves"? Foucault, subjectivity and discourse analysis. *Theory and Psychology,* 20(1):52-75.

Young, J., Hood, C., Woolley, R., Gandesha, A. and Souza, R. (2011) National Audit of Dementia (NAD). *Report of the national audit of dementia care in general hospitals 2011.* Royal College of Psychiatrists online report www.rcpsych.ac.uk/pdf/NAD.

Zangwill, O.L. (1964) Psychopathology of dementia. *Proceedings of the Royal Society of Medicine*, 57:914.

Zarowitz, B.J., O'Shea, T. and Nance, M. (2014) Clinical, demographic and pharmacologic features of nursing home residents with Huntington's disease. *Journal of the Medical Directors Association*, 15(6):423-428.

Zhang, Y. (2018) Governing dementia: a historical investigation of the power of states and professionals in the conceptualisation of dementia in China. *Culture, Medicine and Psychiatry,* 42:862-892.

Zilborg, G. and Henry, G.W. (1941) *History of medical psychology*. New York: Norton.

Appendices

Appendix 1: Literature Review (for Chapter 3) Search on the History of Dementia

Essential	Alternatives	Undesirable (exclusion criteria)
1. Dementia	Alzheimer's Disease; Senility	**Dementia praecox**
AND any one (or more) of the following		
a. History	Truncation – histor*	**Case history; family history; medical history; Life history; Natural history**
b. Definition	Truncation – D=definition*	**Definitions used in assessments of co-morbidity or activities of daily living or carers, clinical Current medical definitions Definitions/discussion not attributed to history**
c. Concept	Truncation – concept*	**Current concepts, contemporary concepts**
d. Terminology	Truncation – term*	**Long term; short term; terminal**
e. Construction	Truncation – construct*	
f. Origins	Truncation – origin*	**Ethnic origin; family origin;**
g. Medicalisation	**Biomedicalisation; Bio-medicalisation**	

Results

	Search Terms		No. Items retrieved	Not relevant	Relevant	Dupl. In this database
	British Nursing Index					
	Ti title	Search fields				
01	Dementia	a. Histor*	3	3	0	0
02	Dementia	b. Definition	3	3	0	0
03	Dementia	c. Concept*	12	12	0	0
04	Dementia	d. Term*	2	2	0	0
05	Dementia	e. Construct*	11	7	**4**	0
06	Dementia	f. Origin*	2	2	0	0
07	Dementia	g. Medicalisation	1	0	**1**	0
08	Alzheimer's	a. Histor*	1	1	0	0
09	Alzheimer's	b. Definition	2	2	0	0
10	Alzheimer's	c. Concept*	6	5	**1**	0
11	Alzheimer's	d. Term*	0	0	0	0
12	Alzheimer's	e. Construct*	3	1	**2**	0
13	Alzheimer's	f. Origin*	2	2	0	0
14	Alzheimer's	g. Medicalisation	0	0	0	0
15	Senility	a. Histor*	0	0	0	0
16	Senility	b. Definition	0	0	0	0
17	Senility	c. Concept*	0	0	0	0
18	Senility	d. Term*	0	0	0	0
19	Senility	e. Construct*	0	0	0	0
20	Senility	f. Origin*	0	0	0	0
21	Senility	g. Medicalisation	0	0	0	0

Articles relevant for inclusion from BNI database (n = 8) excluding duplications (n=0), Total - 8:

- Adams T (1998) The discursive construction of dementia care: implications for mental health nursing. *Journal of Advanced Nursing,* 28(3): 614-621
- Behuniak SM (2011) The living dead? The construction of people with Alzheimer's disease as zombies. *Ageing and Society*, 31: 70-92
- Davis DHJ (2004) Dementia: sociological and philosophical constructions. *Social Sciences and Medicine,* 58: 369-378
- Henderson JN and Henderson LC (2002) Cultural construction of disease: A "supernormal" construct of dementia in an American Indian tribe. *Journal of Cross-Cultural Gerontology,* 17: 197-212
- Lyman KA (1989) Bringing the social back in: a critique of the biomedicalisation of dementia. *Gerontologist,* 29(5): 597-605
- Makoni SB (1999) Multiple linguistic and cultural constructions of dementia in black South Africans. *The Gerontologist, suppl. Special Issue 1.* 39: 477-
- Sabat SR and Harre R (1992) The construction and deconstruction of self in Alzheimer's disease. *Ageing and Society,* 12: 443-
- Watari K and Gatz M (1999) Conceptualisation of Alzheimer's disease and help seeking among Korean Americans. *The Gerontologist, suppl. Special Issue 1.* 39: 586

	Search Terms		**No. Items retrieved**	**Not relevant**	**Relevant**	**Dupl. In this database**
	Medline (hosted by Ebsco publishing)					
	Ti title	Search fields				
01	Dementia	a. Histor*	109	0	**17**	0
02	Dementia	b. Definition*	27	27	1	1
03	Dementia	c. Concept*	125	117	**8**	3
04	Dementia	d. Term*	20	19	**0**	0
05	Dementia	e. Construct*	25	22	**3**	0
06	Dementia	f. Origin*	22	21	**0**	0

07	Dementia	g. Medicalisation	0	0	0	0
08	Alzheimer's	a. Histor*	58	42	**18**	6
09	Alzheimer's	b. Definition	16	15	**2**	1
10	Alzheimer's	c. Concept*	111	108	**6**	4
11	Alzheimer's	d. Term*	69	60	0	0
12	Alzheimer's	e. Construct*	24	24	0	0
13	Alzheimer's	f. Origin*	77	75	**1**	1
14	Alzheimer's	g. Medicalisation	0	0	0	0
15	Senility	a. Histor*	0	0	0	0
16	Senility	b. Definition*	1	0	**1**	0
17	Senility	c. Concept*	1	0	**1**	1
18	Senility	d. Term*	1	0	**1**	0
19	Senility	e. Construct*	0	0	0	0
20	Senility	f. Origin*	2	2	0	0
21	Senility	g. Medicalisation	0	0	0	0

Articles relevant for inclusion from Medline (Ebsco) database (n =59) excluding duplications (n=16), Total - 43 :

- Albert M (2005) Subcortical dementia: historical review and personal review. *Neurocase* 11(4): 243-245(3)
- Amaducci LA, Rocca WA, Schoenberg BS (1986) Origin of the distinction between Alzheimer's disease and senile dementia: how history can classify nosology. *Neurology* 36(11): 1497-9
- Ballenger JF, Nelson JL, Whitehouse PJ (1999) Beyond "progress" in the history of Alzheimer disease. *Alzheimer Disease And Associated Disorders* 13(3): 130-131
- Ballenger JF (2006) Progress in the history of Alzheimer's disease: the importance of context. *Journal of Alzheimer's Disease* 9(3 Suppl.): 5-13
- Beach TG (1987) The history of Alzheimer's disease: three debates. *Journal of the History of Medicine and Allied Sciences* 42(3): 327-349
- Beard RL (2004) Advocating voice: organisational, historical and social milieu of the Alzheimer's disease movement. *Sociology of Health and Illness* 26(6): 797-819

- Berchtold NC and Cotman CW (1998) Evolution in the conceptualisation of dementia and Alzheimer's disease: Greco-Roman period to the 1960s. *Neurobiology of Ageing* 19(3): 173-189
- Berrios GE (1987) Dementia during the seventeenth and eighteenth centuries: a conceptual history. *Psychological Medicine* 17(4): 829-837
- Boling TE and Sommers K (1988) Alzheimer's disease. "A 1980's concept for senility"? *Nursing Homes And Senior Citizen Care* 37(1): 24-27
- Boller F (2008) History of dementia. *Handbook of Clinical Neurology* 89:3-13
- Boller F and Forbes MM (1998) History of dementia and dementia in history: an overview. *Journal of the Neurological Sciences* 158: 125-133
- Brannon WL (1994) Alois Alzheimer (1864-1915).II. Dementia before and after Alzheimer: a brief history. *Journal of the South Carolina Medical Association* 90(9): 402-403
- Burchynsky S (1998) Problems of dementia: the history of formation of ideas about the nature of Alzheimer's disease. *The Ukrainian Historical and Medical Journal* 1997-1998 (7-8) 52-53
- Casanova MF, Struble RG, Whitehouse PJ, Price DL (1998) A historical perspective on the neuropathology of dementia with emphasis on the senile plaque. *Boletin De La Association Médica De Puerto Rico* 80(11): 424-428
- Davis DHJ (2004) Dementia: sociological and philosophical constructions. *Social Sciences and Medicine,* 58: 369-378
- Desmond DW (1996) Vascular dementia: a construct in evolution. *Cerebrovascular and Barin Metabolism Reviews* 8(4): 296-325
- Fukui T (2014) Historical review of academic concepts of dementia in the world and Japan: with a short history of representative diseases. *Neurocase* 2014 Mar 7 [Electronic Publication]
- Förstl H (2005) Uncommon causes of dementia: an historical account. *International Psychogeriatrics* 17 Suppl 1: S3-15
- Fox PJ (1999) Defining dementia: social and historical background of Alzheimer disease. *Genetic Testing* 3(1): 13-19

- George DR, Whitehouse PJ and Ballenger J (2011) The evolving classification of dementia: placing the DSM-V in a meaningful historical and cultural context and pondering the future of “Alzheimer’s”. *Cult Med Psychiatry* 35: 417-435
- Halpert BP (1983) Development of the term “senility” as a medical diagnosis. *Minnesota Medicine* 66(7): 421-424
- Henderson JN and Henderson LC (2002) Cultural construction of disease: A “supernormal” construct of dementia in an American Indian tribe. *Journal of Cross-Cultural Gerontology,* 17: 197-212
- Hinton L, Franz CE, Yeo G, Levkoff SE (2005) Conceptions of dementia in a multi-ethnic sample of family caregivers. *Journal of the American Geriatrics Society* 53(8): 1405-1410
- Jellinger KA (2006) Alzheimer 100 – highlights in the history of Alzheimer research. *Journal of Neural Transmission* 113(11): 1603-1623
- Kassel V (1965) Senility – a definition. *Rocky Mountain Medical Journal* 62(11): 51-52
- Khachaturian Z (2006) History of Alzheimer’s research: the politics of science in building a national program of research. *Alzheimer Disease and Associated Disorders* 20 (3) Suppl. 2: S31-34
- Kurz AF (2000) The concept of dementia: retain, reframe, rename or replace? *International Psychogeriatrics* 22(1): 37-42
- Loeb C (1995) The history of vascular dementia. *Journal of the History of the Neurosciences* 4(2): 121-126
- Lucci B (1998) The contribution of Gaetano Persuni to the definition of Alzheimer’s disease. *Italian Journal of Neurological Sciences* 19(1): 49-52
- Maurer K (2006) Historical background of Alzheimer’s research done 100 years ago. *Journal of Neural Transmission* 113(11): 1597-601
- Maurer K and Hoyer S (2006) Alois Alzheimer revisited: differences in origin of the disease carrying his name. *Journal of Neural Transmission* 113 (11): 1645-1658
- McKhann GM (2011) Changing concepts of Alzheimer disease. *The Journal of the American Medical Association* 305 (23): 2458-9

- Mielke MM, Montine T, Khachaturian AS (2012) Vascular diseases: one pathway toward new conceptual models of dementia. *Alzheimer's and Dementia* 8 Suppl 5, Issue 5 S69-70
- Möller HS and Graeber MB (1998) The case described by Alois Alzheimer in 1911: historical and conceptual perceptions based on the clinical record and neurohistological sections. *European Archives of Psychiatry and Clinical Neurosciences* 248: 111-122
- Neel AW and Ostenfeld I (1946) Contribution to the history of dementia paralytica with special reference to the contributions of Scandinavian, particularly Danish scientists. *Acta Psychiatrica et Neurologica* 21(1-3): 605-642
- Niedermeyer E, Ghigo JO (2011) Alzheimer dementia: an overview and a promising new concept. *American Journal of Electroneurodiagnositic Technology* 51: 82-91
- Ramirez-Bermudez J (2012) Alzheimer's disease: critical notes on the history of a medical concept. *Archives of Medical Research* 43(8): 595-599
- Román G (1999) A historical review of the concept of vascular dementia: lessons from the past for the future. *Alzheimer's Disease and Associated Disorders* 13 Suppl 3: S4-8
- Román G (2003) Vascular dementia: a historical background. *International Psychogeriatrics* 15 Suppl 1: 11-3
- Schwartz MF (1992) The distinction between Alzheimer's disease and senile dementia: historical considerations. *Journal of the History of the Neurosciences* 1(3): 169-187
- Tanzi RE (2013) A brief history of Alzheimer's disease gene discovery *Journal of Alzheimer's Disease* 33 Suppl 1: S5-13
- Vannoy JF, Greene JA (1989) Alzheimer's disease: a brief history. *Journal of the Tennessee Medical Association* 82 (1): 15-17
- Wisniewski HM (1989) Milestones in the history of Alzheimer's disease research. *Progress in Clinical and Biological Research* 317: 1-11

	Search Terms		No. Items retrieved	Not relevant	Relevant	Dupl. In this database
	CINAHL Plus with Text					
	Ti title	Search fields				
01	Dementia	a. Histor*	55	0	1	0
02	Dementia	b. Definition	17	17	0	0
03	Dementia	c. Concept*	75	74	1	0
04	Dementia	d. Term*	10	10	0	0
05	Dementia	e. Construct*	26	24	2	0
06	Dementia	f. Origin*	12	12	0	0
07	Dementia	g. Medicalisation	0	0	0	0
08	Alzheimer's	a. Histor*	47	43	4	1
09	Alzheimer's	b. Definition	5	5	0	0
10	Alzheimer's	c. Concept*	36	35	1	0
11	Alzheimer's	d. Term*	4	4	0	0
12	Alzheimer's	e. Construct*	12	11	1	0
13	Alzheimer's	f. Origin*	9	9	0	0
14	Alzheimer's	g. Medicalisation	0	0	0	0
15	Senility	a. Histor*	1	1	0	0
16	Senility	b. Definition	0	0	0	0
17	Senility	c. Concept*	0	0	0	0
18	Senility	d. Term*	0	0	0	0
19	Senility	e. Construct*	0	0	0	0
20	Senility	f. Origin*	0	0	0	0
21	Senility	g. Medicalisation	0	0	0	0

Articles relevant for inclusion from CINAHL Plus with Text database (n = 10) excluding duplications (n = 1), Total - 9:

- Behuniak SM (2011) The living dead? The construction of people with Alzheimer's disease as zombies. *Ageing and Society* 31: 70-92

- Cipriani G, Dolciotti C, Picchi L, Bonuccelli U (2011) Alzheimer and his disease: a brief history. *Neurological Sciences* 32: 275-279
- Davis DHJ (2004) Dementia: sociological and philosophical constructions. *Social Sciences and Medicine,* 58: 369-378
- George DR, Whitehouse PJ and Ballenger J (2011) The evolving classification of dementia: placing the DSM-V in a meaningful historical and cultural context and pondering the future of "Alzheimer's". *Cult Med Psychiatry* 35: 417-435
- Kurtz AF (2000) the concept of dementia: retain, reframe, rename or replace? *International Psychogeriatrics* 22(1): 37-42
- Lacey D (1999) The evolution of care: A 100-year history of institutionalisation of people with Alzheimer's disease. *Journal of Gerontological Social Work* 31(3/4): 101-131
- McKhann GM (2011) Changing concepts of Alzheimer disease. *The Journal of the American Medical Association* 305 (23): 2458-9
- Tanzi RE (2013) A brief history of Alzheimer's disease gene discovery *Journal of Alzheimer's Disease* 33 Suppl 1: S5-13
- Uppal G and Bonas S (2014) Constructions of dementia in the South Asian community: a systematic literature review. *Mental Health, Religion and Culture* 17(2): 143-160

	Search Terms		**No. Items retrieved**	**Not relevant**	**Relevant**	**Dupl. In this database**
	PsycARTICLES database					
	Ti title	Search fields				
01	Dementia	h. Histor*	0	0	0	0
02	Dementia	i. Definition	0	0	0	0
03	Dementia	j. Concept*	1	1	0	0
04	Dementia	k. Term*	0	0	0	0
05	Dementia	l. Construct*	1	1	0	0

06	Dementia	m. Origin*	0	0	0	0
07	Dementia	n. Medicalisation	0	0	0	0
08	Alzheimer's	h. Histor*	1	1	0	0
09	Alzheimer's	i. Definition	1	1	0	0
10	Alzheimer's	j. Concept*	6	6	0	0
11	Alzheimer's	k. Term*	0	0	0	0
12	Alzheimer's	l. Construct*	0	0	0	0
13	Alzheimer's	m. Origin*	0	0	0	0
14	Alzheimer's	n. Medicalisation	0	0	0	0
15	Senility	h. Histor*	0	0	0	0
16	Senility	i. Definition	0	0	0	0
17	Senility	j. Concept*	0	0	0	0
18	Senility	k. Term*	0	0	0	0
19	Senility	l. Construct*	0	0	0	0
20	Senility	m. Origin*	0	0	0	0
21	Senility	n. Medicalisation	0	0	0	0

Articles relevant for inclusion from database - 0:

- No relevant results found

	Search Terms		**No. Items retrieved**	**Not relevant**	**Relevant**	**Dupl. In this database**
	PsycINFO					
	Ti title	Search fields				
01	Dementia	o. Histor*	95	89	**6**	0
02	Dementia	p. Definition	30	30	0	0
03	Dementia	q. Concept*	113	107	**6**	1
04	Dementia	r. Term*	9	8	1	0
05	Dementia	s. Construct*	37	34	**3**	0
06	Dementia	t. Origin*	11	10	**1**	1

07	Dementia	u. Medicalisation	3	2	1	0
08	Alzheimer's	o. Histor*	39	31	8	0
09	Alzheimer's	p. Definition	13	12	1	0
10	Alzheimer's	q. Concept*	87		4	4
11	Alzheimer's	r. Term*	6	6	0	0
12	Alzheimer's	s. Construct*	29	29	0	0
13	Alzheimer's	t. Origin*	22	20	2	1
14	Alzheimer's	u. Medicalisation	0	0	0	0
15	Senility	o. Histor*	0	0	0	0
16	Senility	p. Definition	0	0	0	0
17	Senility	q. Concept*	0	0	0	0
18	Senility	r. Term*	0	0	0	0
19	Senility	s. Construct*	0	0	0	0
20	Senility	t. Origin*	1	0	1	0
21	Senility	u. Medicalisation	0	0	0	0

Articles relevant for inclusion from PsycINFO database (n = 34) excluding duplications (n = 7), Total - 27:

- Amaducci LA, Rocca WA, Schoenberg BS (1986) Origin of the distinction between Alzheimer's disease and senile dementia: how history can classify nosology. *Neurology* 36(11): 1497-9
- Beard RL (2004) Advocating voice: organisational, historical and social milieu of the Alzheimer's disease movement. *Sociology of Health and Illness* 26(6): 797-819
- Belgrave LL (2004) Living with dementia: lay definitions of Alzheimer's disease among African American caregivers and sufferers. *Symbolic Interaction* 27(2): 199-222
- Berchtold NC and Cotman CW (1998) Evolution in the conceptualisation of dementia and Alzheimer's disease: Greco-Roma period to the 1960's. *Neurobiology of Ageing* 19(3): 173-189
- Berrios GE (1990) Alzheimer's disease: a conceptual history. *International Journal of Geriatric Psychiatry* 5: 355-365
- Blumer G (1907) The history and use of the term dementia. *American journal of Insanity* 63: 337-348

- Bond J (1992) The medicalization of dementia. *Journal of Ageing Studies* 6(4): 397-403
- Davis DHJ (2004) Dementia: sociological and philosophical constructions. *Social Sciences and Medicine,* 58: 369-378
- Forbat L (2003) Concepts and understandings of dementia by 'gatekeepers' and minority ethnic service users. *Journal of Health Psychology* 8(5): 645-655
- Förstl H (2005) Uncommon causes of dementia: an historical account. *International Psychogeriatrics* 17 Suppl 1: S3-15
- George DR, Whitehouse PJ and Ballenger J (2011) The evolving classification of dementia: placing the DSM-V in a meaningful historical and cultural context and pondering the future of "Alzheimer's". *Cult Med Psychiatry* 35: 417-435
- Gottfies CG (1991) Classifying organic mental disorders and dementia: a review of historical perspectives. *International Psychogeriatrics* 3(suppl): 9-17
- Hanson BG (1991) Parts, players and "patienting": The social construction of senile dementia. *Family Systems Medicine* 9(3): 267-274
- Henderson JN and Henderson LC (2002) Cultural construction of disease: A "supernormal" construct of dementia in an American Indian tribe. *Journal of Cross-Cultural Gerontology,* 17: 197-212
- Hinton L, Franz CE, Yeo G and Levkoff SE (2005) Conceptions of dementia in a multi-ethnic sample of family caregivers. *Journal of the American Geriatrics Society* 53: 1405-1410
- Hodges JR (2006) Alzheimer's centennial legacy: origins, landmarks and the current status of knowledge concerning cognitive aspects. *Brain* 129: 2811-2822
- Holstein M (1997) Alzheimer's disease and senile dementia, 1885-1920: An interpretive history of disease negotiation. *Journal of Ageing Studies* 11(1): 1-13
- Kotsovsky D (1929) The origin of senility. *American Journal of Physiology* 90: 419-420
- Kurz AF (2000) The concept of dementia: retain, reframe, rename or replace? *International Psychogeriatrics* 22(1): 37-42

- Lacey D (1999) The evolution of care: a 100-year history of institutionalisation of people with Alzheimer's disease. *Journal of Gerontological Social Work* 31(3-4): 101-131
- Lefroy RB (2000) The legacy of Alois Alzheimer: an historical perspective. *American Journal of Alzheimer's Disease* 15(4) Jul-Aug: 252-255
- Möller HS and Graeber MB (1998) The case described by Alois Alzheimer in 1911: historical and conceptual perceptions based on the clinical record and neurohistological sections. *European Archives of Psychiatry and Clinical Neurosciences* 248: 111-122
- Niedermeyer E (2011) Alzheimer dementia: an overview and a promising new concept. *American Journal of Electroneurodiagnositic Technology* 51: 82-91
- Sachdev P (2000) Is it time to retire the term 'dementia'? *The Journal of Neuropsychiatry and Clinical Neurosciences* 12(2): 276-279
- Shua-Haim JR (1998) Alzheimer's syndrome and not Alzheimer's disease: the historical struggle to define the disease. *American Journal of Alzheimer's Disease* 13(2) Mar-Apr: 92-95
- Spatt J (2003) Arnold Pick's concept of dementia. *Cortex: A Journal Devoted to the Study of the Nervous System and Behaviour* 39(3): 525-531
- Yeo G (2001) Conceptions of dementia among Vietnamese American caregivers. *Journal of Gerontological Social Work* 36(1-2): 131-152

Literature review inclusion summary (Literature search 1 – up to 2014; Literature search 2 - update 2014-2019; and, Manual search, see Section 3.2)

- Adams, T. (1998) The discursive construction of dementia care: implications for mental health nursing. *Journal of Advanced Nursing*, 28(3):614-621.
- Albert, M. (2005) Subcortical dementia: historical review and personal review. *Neurocase,* 11(4): 243-245.
- Amaducci, L.A., Rocca, W.A. and Schoenberg, B.S. (1986) Origin of the distinction between Alzheimer's disease and senile dementia: how history can classify nosology. *Neurology,* 36(11):1497-9.
- Ballenger, J.F. (2000) Beyond the characteristic plaques and tangles: mid-twentieth century U.S. psychiatry and the fight against senility. In: Whitehouse, P.J., Maurer, K. and Ballenger, J.F. (eds.) *Concepts of Alzheimer Disease. Biological, Clinical and Cultural Perspectives.* London*:* The John Hopkins University Press, pp.83-103.
- Ballenger, J.F. (2006) Progress in the history of Alzheimer's disease: the importance of context. *Journal of Alzheimer's Disease,* 9(3 Suppl.):5-13.
- Ballenger, J.F. (2006) *Self, senility, and Alzheimer's Disease in Modern America*. Baltimore: The John Hopkins Press.
- Ballenger, J.F. (2017) Framing confusion: dementia, society and history. *American Medical Association Journal of Ethics*, 19(7):713-719.
- Ballenger, J.F., Nelson, J.L. and Whitehouse, P.J. (1999) Beyond "progress" in the history of Alzheimer disease. *Alzheimer Disease and Associated Disorders* 13(3):130-131.
- Beach, T.G. (1987) The history of Alzheimer's disease: three debates. *Journal of the History of Medicine and Allied Sciences,* 42(3):327-349.
- Beard, R.L. (2004) Advocating voice: organisational, historical and social mileu of the Alzheimer's disease movement. *Sociology of Health and Illness*, 26(6):797-819.
- Behuniak, S.M. (2011) The living dead? The construction of people with Alzheimer's disease as zombies. *Ageing and Society*, 31:70-92.
- Belgrave, L.L. (2004) Living with dementia: lay definitions of Alzheimer's disease among African American caregivers and sufferers. *Symbolic Interaction*, 27(2):199-222.

- Berchtold, N.C. and Cotman, C.W. (1998) Evolution in the conceptualisation of dementia and Alzheimer's disease: Greco-Roman period to the 1960s. *Neurobiology of Ageing,* 19(3):173-189.
- Berrios, G.E. (1987) Dementia during the seventeenth and eighteenth centuries: a conceptual history. *Psychological Medicine,* 17(4):829-837.
- Berrios, G.E. (1990) Alzheimer's disease: a conceptual history. *International Journal of Geriatric Psychiatry,* 5:355-365.
- Berrios, G.E. (1995) Dementia. In: Berrios, G. and Porter, R. (eds.) *A History of Clinical Psychiatry. The Origin and History of Psychiatric Disorders*. London and New Brunswick, NJ: The Athlone Press, pp. 34-51.
- Berrios, G. (2010) Dementia: Historical review. In: Ames, D., Burns, A. and O'Brien, J. (eds.) *Dementia.* (4th ed.) London: Hodder Arnold, pp.5-17.
- Blumer, G. (1907) The history and use of the term dementia. *American Journal of Insanity,* 63:337-348.
- Boling, T.E. and Sommers, K. (1988) Alzheimer's disease. "A 1980's concept for senility"? *Nursing Homes and Senior Citizen Care,* 37(1):24-27.
- Boller, F. (2008) History of dementia. *Handbook of Clinical Neurology,* 89:3-13.
- Boller, F. and Forbes, M.M. (1998) History of dementia and dementia in history: an overview. *Journal of the Neurological Sciences,* 158:125-133.
- Bond, J. (1992) The medicalization of dementia. *Journal of Ageing Studies,* 6(4):397-403.
- Brannon, W.L. (1994) Alois Alzheimer (1864-1915).II. Dementia before and after Alzheimer: a brief history. *Journal of the South Carolina Medical Association,* 90(9):402-403.
- Burchynsky, S. (1998) Problems of dementia: the history of formation of ideas about the nature of Alzheimer's disease. *The Ukrainian Historical and Medical Journal* 1997-1998, (7-8):52-53.
- Casanova, M.F., Struble, R.G., Whitehouse, P.J. and Price, D.L. (1998) A historical perspective on the neuropathology of dementia with emphasis on the senile plaque. *Boletin De La Association Médica De Puerto Rico,* 80(11): 424-428.
- Cipriani, G., Dolciotti, C., Picchi, L. and Bonuccelli, U. (2011) Alzheimer and his disease: a brief history. *Neurological Sciences,* 32:275-279.

- Davis, D.H.J. (2004) Dementia: sociological and philosophical constructions. *Social Sciences and Medicine,* 58:369-378.
- Dening, T. and Sandilyan, M.B. (2015) Dementia: definitions and types. *Nursing Standard*, 29(37):37.
- Desmond, D.W. (1996) Vascular dementia: a construct in evolution. *Cerebrovascular and Brain Metabolism Reviews*, 8(4):296-325.
- Dillman, R.J.M. (2000) Alzheimer disease: Epistemological lessons from history? In: Whitehouse, P.J., Maurer, K. and Ballenger, J.F. (eds.) *Concepts of Alzheimer Disease. Biological, Clinical and Cultural Perspectives.* London: The John Hopkins University Press, pp.129-157.
- Engelhardt, E. and Grinberg, L.T. (2015) Alzheimer and vascular brain disease: senile dementia. *Dementia and Neuropsychologia*, 9(2):184-188.
- Forbat, L. (2003) Concepts amd understandings of dementia by 'gatekeepers' and minority ethnic service users. *Journal of Health Psychology*, 8(5):645-655.
- Förstl, H. (2000) Contributions of German neuroscience to the concept of Alzheimer disease. In: Whitehouse, P.J., Maurer, K. and Ballenger, J.F. (eds.) *Concepts of Alzheimer Disease. Biological, Clinical and Cultural Perspectives.* London: The John Hopkins University Press, pp. 72-82.
- Förstl, H. (2005) Uncommon causes of dementia: an historical account. *International Psychogeriatrics,* 17 Suppl 1:S3-15.
- Fox, P.J. (1999) Defining dementia: social and historical background of Alzheimer disease. *Genetic Testing,* 3(1):13-19.
- Fukui, T. (2014) Historical review of academic concepts of dementia in the world and Japan: with a short history of representative diseases. *Neurocase,* 2014 Mar 7 [Electronic Publication].
- George, D.R., Whitehouse, P.J. and Ballenger, J. (2011) The evolving classification of dementia: placing the DSM-V in a meaningful historical and cultural context and pondering the future of "Alzheimer's". *Culture, Medicine and Psychiatry,* 35:417-435.
- Gerbaldo, H. (2000) Auguste D: The history of Alois Alzheimer's first case. In: Whitehouse, P.J., Maurer, K. and Ballenger, J.F. (eds.) *Concepts of Alzheimer Disease. Biological, Clinical and Cultural Perspectives.* London: The John Hopkins University Press, pp.5-29.
- Gottfies, C.G. (1991) Classifying organic mental disorders and dementia: a review of historical perspectives. *International Psychogeriatrics,* 3 (suppl):9-17.

- Gubrium, J.F. (1986) *Oldtimers and Alzheimer's: The descriptive organisation of senility*. Greenwhich, Connecticut and London: JAI Press.
- Halpert, B.P. (1983) Development of the term "senility" as a medical diagnosis. *Minnesota Medicine,* 66(7):421-424.
- Hanson, B.G. (1991) Parts, players and "patienting": The social construction of senile dementia. *Family Systems Medicine,* 9(3):267-274.
- Harding, N. and Palfrey, C. (1997) *The Social Construction of Dementia: Confused Professionals?* London: Jessica Kingsley.
- Henderson, J.N. and Henderson, L.C. (2002) Cultural construction of disease: a "supernormal" construct of dementia in an American Indian tribe. *Journal of Cross-Cultural Gerentology*, 17:197-212.
- Hilton, C. (2015) Psychiatrists, mental health provision and 'senile dementia' in England, 1940's-1979. *History of Psychiatry,* 26(2): 182-199.
- Hinton, L., Franz, C.E., Yeo, G. and Levkoff, S.E. (2005) Conceptions of dementia in a multi-ethnic sample of family caregivers. *Journal of the American Geriatrics Society*, 53(8):1405-1410.
- Hodges, J.R. (2006) Alzheimer's centennial legacy: origins, landmarks and the current status of knowledge concerning cognitive aspects. *Brain,* 129:2811-2822.
- Holstein, M. (1997) Alzheimer's disease and senile dementia, 1885-1920: An interpretive history of disease negotiation. *Journal of Ageing Studies,* 11(1):1-13.
- Holstein, M. (2000) Ageing, culture, and the framing of Alzheimer disease. In: Whitehouse, P.J., Maurer, K. and Ballenger, J.F. (eds.) *Concepts of Alzheimer Disease. Biological, Clinical and Cultural Perspectives.* London: The John Hopkins University Press, pp.158-180.
- Ingram, J. (2014) *The end of memory: a natural history of aging and Alzheimer's*. London: Penguin Random House.
- Jebelli, J. (2017) *In pursuit of memory: the fight against Alzheimer's.* London: John Murray.
- Jellinger, K.A. (2006) Alzheimer 100 – highlights in the history of Alzheimer research. *Journal of Neural Transmission,* 113(11):1603-1623.

- Jellinger, K.A. (2018) Dementia with Lewy bodies and Parkinson's disease – dementia: current concepts and controversies. *Journal of Neural Transmission*, 125(4):615-650.
- Kassel, V. (1965) Senility – a definition. *Rocky Mountain Medical Journal,* 62(11):51-52.
- Katzman, R. and Bick, K.L. (2000) The rediscovery of Alzheimer disease during the 1960s and 1970s. In: Whitehouse, P.J., Maurer, K. and Ballenger, J.F. (eds.) *Concepts of Alzheimer Disease. Biological, Clinical and Cultural Perspectives.* The John Hopkins University Press: London, pp. 104-114.
- Keuck, L. (2018) History as a biomedical matter: recent reassessments of the first cases of Alzheimer's disease. *History and Philosophy of the Life Sciences*, 40(1):10.
- Khachaturian, Z. (2006) Hostory of Alzheimer's research: the politics of science in building a nationa program of research. *Alzheimer Disease and Associated Dosorders*, 20(3), Suppl.2: S31-34.
- Kitwood, T. (1995) Dementia. In: Berrios, G. and Porter, R. (eds.) *A History of Clinical Psychiatry. The Origin and History of Psychiatric Disorders*. London and New Brunswick, NJ: The Athlone Press, pp.63-71.
- Kotsovsky, D. (1929) The origin of senility. *American Journal of Physiology,* 90:419-420.
- Kurz, A.F. (2000) The concept of dementia: retain, reframe, rename or replace? *International Psychogeriatrics,* 22(1):37-42.
- Lacey, D. (1999) The evolution of care: a 100-year history of institutionalisation of people with Alzheimer's disease. *Journal of Gerontological Social Work,* 31(3-4):101-131.
- Lefroy, R.B. (2000) The legacy of Alois Alzheimer: an historical perspective. *American Journal of Alzheimer's Disease,* 15(4):252-255.
- Lock, M. (2013) The Alzheimer Conundrum: Entanglements of Dementia and Ageing. Oxfordshire: Princeton University Press.
- Loeb, C. (1995) The history of vascular dementia. *Journal of the History of the Neurosciences,* 4(2):121-126.
- Lucci, B. (1998) The contribution of Gaetano Perusini to the definition of Alzheimer's disease. *Italian Journal of Neurological Sciences,* 19(1):49-52.
- Lyman, K.A. (1989) Bringing the social back in: a critique of the biomedicalisation of dementia. *The Gerentologist,* 29(5):597-605.

- Maurer, K., Volk, S. and Makoni, S.B. (1999) Multiple linguistic and cultural constructions of dementia in black South Africans. *The Gerentologist*, suppl. Special Issue 1, 39:477.
- Maurer, K. (2006) Historical background of Alzheimer's research done 100 years ago. *Journal of Neural Transmission,* 113(11):1597-601.
- Maurer, K. and Hoyer, S. (2006) Alois Alzheimer revisited: differences in origin of the disease carrying his name. *Journal of Neural Transmission,* 113(11):1645-1658.
- McKay and Counts, E. (2017) Multi-infarct dementia: a historical perspective. *Dementia and Geriatric Cognitive Disorders extra*. 7(1):160-171.
- McKhann GM (2011) Changing concepts of Alzheimer disease. *The Journal of the American Medical Association,* 305(23):2458-2459.
- Mielke, M.M., Montine, T. and Khachaturian, A.S. (2012) Vascular diseases: one pathway toward new conceptual models of dementia. *Alzheimer's and Dementia*, 8 Suppl 5, Issue 5:S69-70.
- Möller, H.J. and Graeber, M.B. (1998) The case described by Alois Alzheimer in 1911: historical and conceptual perceptions based on the clinical record and neurohistological sections. *European Archives of Psychiatry and Clinical Neurosciences,* 248:111-122.
- Möller, H.J. and Graeber, M.B. (2000) Johann F: The historical relevance of the case for the concept of Alzheimer disease. In: Whitehouse PJ, Maurer K and Ballenger JF (Eds) *Concepts of Alzheimer Disease. Biological, Clinical and Cultural Perspectives.* London: The John Hopkins University Press, pp.30-46.
- Mueller, C., Ballard, C., Corbett, A. and Aarsland, D. (2017) Historical landmarks in dementia with Lewy bodies. *The Lancet: Neurology*, 16(5):348.
- Neel, A.W. and Ostenfeld, I. (1946) Contribution to the history of dementia paralytica with special reference to the contributions of Scandinavian, particularly Danish scientists. *Acta Psychiatrica et Neurologica*, 21(1-3):605-642.
- Niedermeyer, E. and Ghigo, J.O. (2011) Alzheimer's disease: critical notes on the history of a medical concept. *American Journal of Electroneurodiagnostic Technology*, 51:82-91.
- Ohry, A. and Buda, O. (2015) Teofil Simchowicz (1879-1957): the scientist who coined senile plaques in neuropathology. *Romanian Journal of Morphology and Embryology*, 54(4):1545-1548.

- Papavramidou, N. (2018) The ancient history of dementia. Neurological sciences, 39(11):2011-2016.
- Pollen, D.A. (2000) The history of the genetics of Alzheimer disease. In: Whitehouse, P.J., Maurer, K. and Ballenger, J.F. (eds.) *Concepts of Alzheimer Disease. Biological, Clinical and Cultural Perspectives.* London: The John Hopkins University Press, pp.115-124.
- Porter, R. (1995) Dementia. In, Berrios G and Porter R (Eds) *A History of Clinical Psychiatry. The Origin and History of Psychiatric Disorders*. London and New Brunswick, NJ: The Athlone Press, pp.52-62.
- Post, S.G. (2000) The concept of Alzheimer disease in a hypercognitive society. In: Whitehouse, P.J., Maurer, K. and Ballenger, J.F. (eds.) *Concepts of Alzheimer Disease. Biological, Clinical and Cultural Perspectives.* London: The John Hopkins University Press, pp.245-256.
- Ramirez-Bermudez, J. (2012) Alzheimer's disease: critical notes on the history of a medical concept. *Archives of Medical Research,* 43(8):595-599.
- Ren, R-J., Huang, Y., Xu, G., Li, C-B., Cheng, Q., Chen, S-D. and Wang, G. (2012) History, present and progress of frontotemporal dementia in China: a systematic review. *International Journal of Alzheimer's Disease*. Article ID 587215, doi: 10.1155/2012/587215 [Electronic].
- Román, G. (1999) A historical review of the concept of vascular dementia: lessons from the past for the future. *Alzheimer's Disease and Associated Disorders,* 13 Suppl 3:S4-8.
- Román, G. (2003) Vascular dementia: a historical background. *International Psychogeriatrics,* 15 Suppl 1:11-3.
- Sabat, S.R. and Harre, R. (1992) The construction and deconstruction of self in Alzheimer's disease. *Ageing and Society*, 12:443-461.
- Sachdev, P. (2000) Is it time to retire the term 'dementia'? *The Journal of Neuropsychiatry and Clinical Neurosciences,* 12(2):276-279.
- Schwartz, M.F. (1992) The distinction between Alzheimer's disease and senile dementia: historical considerations. *Journal of the History of the Neurosciences,* 1(3):169-187.
- Shua-Haim, J.R. (1998) Alzheimer's syndrome and not Alzheimer's disease: the historical struggle to define the disease. *American Journal of Alzheimer's Disease,* 13(2):92-95.

- Spatt, J. (2003) Arnold Pick's concept of dementia. *Cortex: A Journal Devoted to the Study of the Nervous System and Behaviour*, 39(3):525-531.
- Tanzi, R.E. (2013) A brief history of Alzheimer's disease gene discovery. *Journal of Alzheimer's Disease,* 33 Suppl 1: S5-13.
- Torack, R.M. (1983) The early history of senile dementia. In: Reisberg, B. (ed.) *Alzheimer's Disease* New York: The Free Press, pp. 23-28.
- Uppal, G. and Bonas, S. (2014) Constructions of dementia in the South Asian community: a systematic literature review. *Mental Health, Religion and Culture*, 17(2):143-160.
- Vannoy, J.F. and Greene, J.A. (1989) Alzheimer's disease: a brief history. *Journal of the Tennessee Medical Association,* 82(1):15-17.
- Vinters, H.V. (2015) Emerging concepts in Alzheimer's disease. *Annual Review of Pathology: Mechanisms of Disease,* 10(1):291-319.
- Watari, K. and Gatz, M. (1999) Conceptualisation of Alzheimer's disease and help seeking among Korean Americans. *The Gerentologist,* suppl. Special Issue 1. 39:58 .
- Whitehouse, P.J. (2000) history and the future of Alzheimer disease. In: Whitehouse, P.J., Maurer, K. and Ballenger, J.F. (eds.) *Concepts of Alzheimer Disease. Biological, Clinical and Cultural Perspectives.* London: The John Hopkins University Press, pp.291-305.
- Wisniewski, H.M. (1989) Milestones in the history of Alzheimer's disease research. *Progress in Clinical and Biological Research*, 317:1-11.
- Woll, A. (2016) Is aging the new disease? *International Conferences on Advances in Computer-Human Interactions,* 2016: 20-28.
- Yeo, G. (2001) Conceptions of dementia among Vietnamese American caregivers. *Journal of Gerentological Social Work*, 36(1-2):131-152.

Appendix 2: Summary of Key Historical Points taken and listed from Chapter 3 History of Dementia Literature Review

*note: Dates given are from those provided by cited authors and consequently there is at times a lack of agreement concerning the dates shown between them – see for example Pythagoros (where 600 or 700 BC is given), and Cicero (where 45 or 44 BC is given)

**note: The date range for Chaucer relates to citing authors providing the birth and death year (1343-1400) rather than a publication of work date. Here, the cited work appears in his uncompleted work *The Canterbury Tales* which was more likely written c.1375-1400, noted by square brackets.

***note: This table is to be used only as a summary, or quick reference guide, listing some of the main events or findings in the history of dementia as highlighted by some of the authors from our literature review in chapter 3. The 'cited by column' provides reference to the citing author who chose to select this 'discovery', 'idea,' or 'breakthough' as important in the history of dementia. It is a list therefore to complement the findings in Chapter 3 and is not a detailed historical account. This explains why sometimes some citing authors are referred to many times (i.e. Jebelli, 2017), often, as in this example, singularly, whilst in others areas, the names of many others are given. As a quick guide, this list is not inclusive of all works, it is just a rough guide and should be viewed only in this light.

Year	Ideas, discoveries or breakthroughs	as cited by
2000 BCE	Ancient Egyptians understood that age could be accompanied by some form of memory disorder.	(Boller, 2008; Boller and Forbes, 1998; George, *et al.,* 2011b).
1500 BCE	The Ebers papyrus contains a brief and possibly the first mention of senile deterioration.	(Loeb, 1995).
700/600 BCE*	Pythagoras, a sixth-centry mathematician, argued people over 63 reached senium, which was characterised by imbecility, an inevitable consequence of old age. In addition he argued that the last two stages of the life cycle caused 'regression of mental capacities'.	(Berchtold and Cotman, 1998; Fukui, 2014; Jebelli, 2017).

500 BCE	Solon, a Greek judge, took senile cognitive decline into account when revising laws.	(Berchtold and Cotman, 1998; Boller, 2008; Boller and Forbes, 1998; Brannon, 1994; Cassanova *et al.,* 1988; Fox, 1989; George, *et al.,* 2011b; Torack, 1984; Vannoy and Greene, 1989).
460-377 BCE	Hippocrates argued 'paranoia' represented the deterioration of mental faculties in the state of old age, although this did not appear in his inventory of mental disorders.	(Berchtold and Cotman, 1998; Fukui, 2014; Torack, 1984).
380 BCE	Plato and his student Aristotle argued old age is inseparable from mental failure In *The Republic* Plato recognised dementia in old age.	(Berchtold and Cotman, 1998; Boller and Forbes, 1998; Brannon, 1994; Fukui, 2014; Porter, 1995; Torack, 1984).
200 – 150 BCE	Galen, a Greek physician also known as Aelius Galenus, used the term 'morosis'(mental slowness) in *De Symptomatum differentis liber,* to describe dementia, listing old age as when it may occur and identifying it as a mental disease	(Berchtold and Cotman, 1998; Brannon, 1994; Cipriani, *et al.,* 2011; Fox, 1989; Fukui, 2014; Loeb, 1995; Schwartz and Stark, 1992; Jebelli, 2017; Torack, 1984).
45/44 BCE*	Cicero, a Roman philosopher in *De Senctute* [How to Grow Old: Ancient wisdom for the second half of life], argued old age did not always mean mental decline and dementia was used as a synonym of madness. It only affected those who are weak in spirit and will.	(Berchtold and Cotman, 1998; Fukui, 2014; Loeb, 1995; Blumer, 1907; Berrios, 2010; Boller, 2008; Boller and Forbes, 1998; Jebelli, 2017; Porter, 1995; Torack, 1984).
25 BCE-50/100 CE	Celsus wrote *De Medicina* and discussed how infections could lead to dementia syndromes.	(Cohen, 1983; Förstl, 2005; Fox, 1989; Porter, 1995).
200 CE	Aretheus of Cappadocia distinguished between acute and chronic neurological and psychiatric disorders	(Boller, 2008; Boller and Forbes, 1998; Schwartz and Stark, 1992).
800-900 CE	Alcuin noted that prevailing doctrines inlcuded mental illness as supernatural, expressions of the devil, and were conveyed through witches.	(Loeb, 1995).
1290s	Bacon wrote both *Methods for Preventing the Appearance of Senility*, and *On the Cure of Old Age and the Preservation of Youth*, noting	(Berchtold and Cotman, 1998; Boller, 2008; Fukui, 2014; Porter, 1995).

	old age is the home for forgetfulness and that senility is the consequence of original sin.	
1343-1400**	Chaucer commented on the inevitability of dementia.	(Berchtold and Cotman, 1998; Fukui, 2014).
1549	Jaso de Pratis wrote the first textbook on neurology, *De Cerebri Morbis,* including a chapter on dementia.	(Fukui, 2014).
1564-1616	Shakespeare made numerous descriptions of dementia in plays including *Hamlet, King Lear, As You Like It*, and *Macbeth.*	(Berchtold and Cotman, 1998; Boller and Forbes, 1998; Brannon, 1994; Fukui, 2014; Ingram, 2014; Lock, 2013).
1583	Barrough's textbook *The Methode of Phisicke* included a section on memory loss and loss of reason.	(Berchtold and Cotman, 1998; Förstl, 2005; Fukui, 2014).
1592	Cosin provided a definition of dementia.	(Berrios, 1987; Förstl, 2005; Porter, 1995).
1595	Janssen invents the compound microscope, supporting later investigations into dementia.	(Boller, 2008).
1597	Du Laurens writes the *Discourse of the Preservation of the Sight; of Melancholic Diseases; of Rheums and Old Age.*	(Porter, 1995).
1615	Adams, in *Mystical Bedlam,* identified 3 groups of psychotic disorders including one potentially akin to dementia.	(Berrios, 1987).
1621	Burton wrote *The Anatomy of Melancholy.*	(Porter, 1995).
1644	The *Oxford English Dictionary* included a definition of dementia.	(Berrios, 1995; 2010).
1672	Willis was argued to be thr first person to observe a correlation between brain atrophy and cognitive impairment.	(Förstl, 2005).
1672	Schneider delivered one of the earliest extensive treatise on vascular dementia.	(Förstl, 2005).
1681 / 1694	Salmon's book, *Iatricia* discussed the concept of senile dementia.	(Berrios, 1987; Porter, 1995).
1684	Willis, in *Practice of Physick* attempted to classify the dementias.	(Berchtold and Cotman, 1998; Berrios, 1987; Berrios, 1995; Berrios, 2010; Loeb, 1995).

1726	Blanchard's popular *Physical Dictionary* adopts the term dementia, defined as anoea or extinction of the imagination and judgement.	(Berrios, 1987; 1995; 2010; Sachdev, 2000).
1726	In the fictional work of Swifts *Gulliver's Travels,* cognitive and personality changes in old age are portrayed.	(Boller and Forbes, 1998; Brannon, 1994; Porter, 1995).
1754	Diderot and d'Alambert provide an entry on 'démence' [providing a medical definition of dementia] in the *French Encyclopaedia.*	(Berrios, 1987; 1995; 2010; Boller and Forbes, 1998).
1772	Boissier de Sauvages, in *Nosologie Methodique* listed the majority of psychiatric illness under the term dementia	(Loeb, 1995).
1776	Cullen reclassified diseases, placing senile dementia under the neuroses, under what he termed 'amentia senilis'. This was argued to br the first time it appeared as a medical entity.	(Berchtold and Cotman, 1998).
1778	Cullen further subdivided vesania (or insanity) into 3 main types- innate, senile and accidental.	(Loeb, 1995).
1785	Cullen wrote *Institutiones de Medicine-Pratique.*	(Berrios, 1987).
1791	Sobrino defined dementia in his Spanish-French dictionary	(Berrios, 1987; 1995; 2010).
1793	Baillie in his textbook on *The Morbid Anatomy of Some of the Most Important Parts of the Human Body Pathology* commented on cerebral atrophy in an aged 'demented' individual.	(Berchtold and Cotman, 1998).
1797	Pinel used the term 'démence' arguing it to mean 'out of one's mind', [although as noted above, some writers argue that as a term it had already been in use, appearing in the *Oxford Dictionary* of 1664].	(Torack, 1983; Berrios, 1996; George, Whitehouse and Ballenger, 2011; Jebelli, 2017).
1801	Pinel spoke of the 'incurability of the dementia originating in old age' in *Traitè Médico-Philosophique sur l'Aliénation Mentale, ou la Maine*	(Beach, 1987).

1805	Esquirol doctoral study *Des Passions*, using the word dementia.	(Berrios, 1995; 2010).
1806	Pinel produced a *Treatise on Insanity.*	(Berchtold and Cotman, 1998; Berrios, 2010; Cipriani, *et al.,* 2011).
1814	Esquirol wrote on *Démence,* I, *Dictionaire des sciences médicales, par une Societé de Médicins et de Chirurgiens.*	(Berrios, 1995; 2010).
1816	Pinel's *Nosografia filosofica o il metedo dell'analisi applicator alla medicina,* provided a medical identification of dementia.	(Loeb, 1995).
1817	Parkinson reported on 6 patients with 'shaking palsy' – now termed Parkinson disease, and has also been associated with PDD and DLB, in his work *An Essay on the Shaking Palsy.*	(Förstl, 2005; Fukui, 2014).
1818	Heinroth in the *Textbook of Disturbances of Mental Life* (German – translated into English in 1975), used the term dementia but in a very broad sense.	(Berrios, 2010).
1822	Bayle, in *Recherches Sur Les Mentales,* used the term 'arachnitis chronique' (now 'General paralysis of the insane' and sometimes used to describe syphilis dementia).	(Berrios, 1995; 2010).
1823	Rostan, in *Recherches Sur Le Ramollissement Du Cerveau, 2nd ed.,* considered brain softening as leading to dementia.	(Berrios, 1995; 2010).
1826	Bayle wrote *Traité Des Maladies Du Cerveau.*	(Berrios, 1995; 2010).
1829	Esquire in *Della Alienazione Mentalle o della Pazzia in genere e in ispecie,* was the first to tackle the clinical problem of dementia on a scientific basis, as well as looking at the age of the patient.	(Loeb, 1995).
1834	Hartley wrote on dotage and attempted to provide an anatomical explanation of dementia.	(Berrios, 1987).
1834	Combe, in *Observations on Mental Derangement,* argued in old age the brain has lost much of its activity by natural decay.	(Schwartz and Stark, 1992).

1837	Pritchard, in A Treatise on Insanity and Other Disorders Affecting the Mind, discussed dementia.	(Cassanova, *et al.,* 1988).
1838	Jean-Étienne Esquirol, student of Pinel, provided a description of senile dementia in *Traité des Maladies Mentales* as resulting from the passage of age. He also distinguished dementia from amentia (learning disability) by arguing 'a demented man has lost the goods he used to enjoy; he is a wealthy person turned poor. An idiot, by contrast, has always been unfortunate and poor'.	(Beach, 1987; Berrios, 1995; Berrios, 2010; Boller, 2008; Boller and Forbes, 1998; Schwartz and Stark, 1992). (Cipriani, *et al.,* 2011; Boller, 2008:4; Jebelli, 2017).
1843	Durand-Fardel in *Traité Du Ramollissement Du Cerveau* looked at brain softening leading to dementia and linked this to strokes.	(Berrios, 1995; 2010).
1845	Griesinger attributed senility to arteriosclerosis.	(Loeb, 1995).
1851	Virchow introduced the term 'amyloid'	(Cassanova, *et al.,* 1988).
1854	Gratiolet named the lobes of the brain.	(Berrios, 1995).
1854	Rudolf Virchow coined the term 'amyloid' deriving from the latin *amylum* for starch and the Greek suffix *–oid* for like. (Although Virchow had thought this was a type of sugar, it would later be found to be a type of protein).	(Jebelli, 2017)
1857	German psychiatrists discovered that general paresis was connected to syphilitic infections [now known to be a form of dementia]	(Ballenger, 2006).
1857	William Tuke, in *Laws of Health*, argued against the widely held idea that old age must be wretched and that suffering has no connection with old age.	(Ingram, 2014)
1860	Morel, in *Traités des Maladies Mentales* noted loss in brain weight was a constant feature in dementia and is also present in ageing.	(Berchtold and Cotman, 1998); Berrios, 1995; 2010).
1861	Griesinger, in *Mental Pathology and Therapeutics,* defined dementia.	(Berrios, 2010; Blumer, 1907).
1862	Translation of Pinel's work of 1801 by Davis.	(Beach, 1987).

1863	Marcé in *Recherches Cliniques et anayomo-pathologiques sure la démence senile et sure les differences que la séparent de la paralysie general,* wrote that dementia was a disease seen in persons over 60 years. He also attempted to differentiate between general paralysis (form of dementia) and senile dementia.	(Berrios, 2010; Cassanova. *et al.,* 1988; Förstl, 2000).
1863	Kahlbaum in *Die Gruppierung der psychischen Krankheiten* uses the term 'aphrenia' for dementia.	(Berrios, 1995; 2010).
1864	Wilks provided the first definitive description of atrophy.	(Berchtold and Cotman, 1998).
1864	Bert, a zoologist, provides what is considered the first recorded parabiosis experiment – leading to future developments and rationale for ideas about blood transfusions and regenerations in Alzheimer's disease.	(Jebelli, 2017)
1872	Jean-Martin Charcot changed the name of the condition 'shaking palsy' to Parkinson's disease'	(Fukui, 2014).
1873	Silver staining (reazionne near) discovered by Golgi. Later used as a technique to examine pathology in dementia.	(Berchtold and Cotman, 1998); Fukui, 2014).
1873	Sheppard, in *Lectures on Madness in its Medical, Legal and Social Aspects*, was the first to report dementia in a younger people.	(Cassanova, *et al.,* 1988).
1874	George Beard, an American neurologist, linked mental decline with age in his text Legal Responsibility in Old Age, arguing ultimately that old age was unproductive.	(Beach, 1987; Ingram, 2014).
1875	Fournier put forward the idea that general paralysis might be related to syphilis.	(Berrios, 1995).
1879	Maudsley's *The Pathology of the Mind* summarised senile insanity as accompanying old age.	(Schwartz and Stark, 1992; Blumer, 1907).

1881	Charcot and Loomis linked dementia to old age in *Clinical Lectures on the Diseases of Old Age.*	(Beach, 1987; 1995; 2010; Förstl, 2005).
1881	Ball and Chambard, in *Démence Apoplectique*, introduced the concept of 'apoplectic dementia' (a form of vascular dementia).	(Berrios, 1995; 2010; Förstl, 2005).
1881	Wernicke, in *Lehrbuch der Gehirnkrankheiten* looked at thiamine deficiency, later linked to dementia.	(Förstl, 2005).
1882	Blocq and Marinesco first identified senile plaques	(Cipriani, *et al.,* 2011).
1883	Kraeplin first described cognitive impairment caused by cerebrovascular disease by naming it arteriosclerotic dementia	(Fukui, 2014).
1883	Clouston in *Clinical Lectures on Mental Diseases* defines dementia.	(Blumer, 1907).
1885	Kraft-Ebing described cellular and vascular alterations.	(Loeb, 1995).
1887	Spitzka, in *Manual of Insanity* defines dementia.	(Blumer, 1907).
1887	Korsakoff in *Ob Alkoholnom* continued the work of Wernicke's alcohol, thiamine deficiency and dementia, now known as Korsakoff dementia.	(Förstl, 2005).
1889	Belijahow reported on the relationship between plaques and dementia	(Berrios, 1995; 2010); Förstl, 2000; Ramirez-Bermudez, 2012).
1892	Blocq and Marinesco identified senile plaques.	(Amaducci *et al.,* 1986; Beach, 1987; Berchtold and Cotman, 1998; Boller and Forbes, 1998; Förstl, 2005; Förstl, 2000; Ohry and Buda, 2015).
1892	Pick, in *Uber die beziehungen der senilen hirnatrophie zur aphasie*, discussed focal lobar atrophy (as opposed to general, diffused atrophy).	(Berrios, 1995; 2010); Boller and Forbes, 1998; Förstl, 2000; 2005; Fukui, 2014; Schwartz and Stark, 1992).
1892	Littré and Robins *Dictionary of Medicine and Surgery,* described dementia of old age	(Loeb, 1995).

	atheromatous alteration of nervous cells and tubules, multiple softenings and haemorrhages	
1894	Binswanger, in *Die Abgrenzung der Allgemein Progressive Paralyze*, gave his name to a dementia thought to be caused by arteriosclerotic demyelination of sub-cortical white matter.	(Beach, 1987; Förstl, 2000; 2005; Fukui, 2014).
1894	Nissl joined Alzheimer at his Frankfurt clinic and discovered 'Nissl stain' allowing visualisation of the cell body of neurons.	(Boller, 2008).
1895	Nötzli proposed the fundamental cause of senile dementia as arteriosclerosis.	(Beach, 1987).
1895	Spratling designated the epoch of 'senility' as the physiological loss of mind/ dementia.	(Holstein, 1997).
1897	Clarke, in *On Huntington's Chorea* described how cortical pathology can cause mental dysfunction.	(Albert, 2005).
1898	Redlich, in *Ueber Miliare Sklerose der Hirnrinde bei Senile Atrophie* found senile plaques, which he called military sclerosis, in 2 cases of senile dementia.	(Amaducci, *et al.,* 1986; Berchtold and Cotman, 1998; Boller, 2008; Cassanova, *et al.,* 1988; Cipriani, *et al.,* 2011; Förstl, 2000; 2005; Schwartz and Stark, 1992).
1898	Clouston's textbook on psychiatry, *Mental Diseases,* 5th edition, included a chapter on senile insanities.	(Beach, 1987).
1898	Alzheimer, in *Neuere Arbeiten über die Dementia Senilis und die Auf Atheromatöser Gefässerkrankung basierenden Gehirnkrankheiten,* discussed vascular brain changes in dementia.	(Förstl, 2000; 2005).
1899	Kraeplin suggests the possibility of presenile dementia in the 6th edition of his textbook on psychiatry *Compendium der Psychiatrie.*	(Amaducci, *et al.,* 1986; Förstl, 2000).
1901	Pick, in *Senile Hirnatrophie als Grundlage von Herderscheinungen* described his second reported case.	(Berrios, 2010; Förstl, 2000).
1901	On the 26th November 1901, Dr Alois Alzheimer met the newly admitted Auguste	(Jebelli, 2017).

	Deter (first patient to be diagnosed with what later will be named Alzheimer's disease).	
1902	Gowers, in *Abiotrophy*, developed a theory of abiotrophy.	(Beach, 1987).
1902	Alzheimer, in *Die Seelenstörungen auf Arterioklerotischer Grundlage,* named a type of vascular dementia as Biswanger's disease and discussed vascular brain changes in dementia.	(Förstl, 2000; 2005).
1902	Russell, in *Senility and Senile Dementia,* argued old age inevitably affected the mind.	(Holstein, 1997).
1902	Pick described lobar atrophy.	(Sachdev, 2000).
1902	In May 1902, Auguste Deter's condition had deteriorated: Alzheimer recorded his final entry in her medical notes describiong her behavioural symptoms.	(Jebelli, 2017).
1903	Bielschowsky improved Golgi's silver staining technique to identify neurofibrils (now known as Bielschowsky stain)	(Berchtold and Cotman, 1998; Förstl, 2000; Fukui, 2014).
1904	Nissl and Alzheimer – published reports on the histopathology of general paresis [now known as a form of dementia].	(Beach, 1987).
1904	Kraeplin, in *Lehrbuch der Psychiatrie* considered the work of Nissl and Alzheimer and argued that general paresis follows the disease of syphilis.	(Beach, 1987).
1904	Pickett, in *Senile Dementia: a Clinical Study of Two Hundred Cases with Particular Regard to Types of the Disease,* found senile dementia was a direct result of cerebral deterioration in old age.	(Beach, 1987; Holstein, 1997).
1905	Osler and his notorious *'The Fixed Period'* speech, the title of his last address at John Hopkins University Medical School, repeated the work of Beard and suggested old men should be chloroformed at 60.	(Beach, 1987; Ingram, 2014)
1905	Bolton, in *Amentia and Dementia: A Clinico-pathological Study,* argued wasting of the	(Cassanova, *et al.,* 1988).

	prefrontal region as the most salient feature in mental deficiency.	
1906	6th June 1906 Auguste Deter died and Alzheimer requested her brain be sent to him at his laboratory in Munich.	(Jebelli, 2017)
1906	Alzheimer reported his findings of 51 year old August Deter, at a meeting of the South-West German Psychiatrists in Tübingen. His talk was titled *'On a Peculiar Disease of the Cerebral Cortex'.*	(Ballenger, 2006; Beach, 1987; Boller, 2008; Cassanova, *et al.,* 1988; Cipriani, *et al.,* 2011; George, Whitehouse and Ballenger, 2011; Hodges, 2006; Holstein, 1997; Möller and Graeber, 1998; Sachdev, 2000; Ramirez-Bermudez, 2012; Tanzi 2013; Förstl, 2000; Jebelli, 2017).
1907	Alzheimer publishes his first report titled *Uber Eine Eigenartige Erkrankung der Hirnrinde* [translated as A unique illness involving the vertebral cortex].	(Amaducci, *et al.,* 1986; Ballenger, 2006; Berrios, 1995; 2010; Cipriani, *et al.,* 2011; Fox, *et al.,* 1999; Hodges, 2006; Loeb, 1995; Schwartz and Stark, 1992; Ramirez-Bermudez, 2012; Shua-Haim and Ross, 1998; Maurer, *et al.,* 2000; Möller and Graeber, 2000; Förstl, 2000).
1907	Fischer, in Miliäre Nekrosen mit Drugsigen Wucherungen der Neurofibrillen, eine Regelmässige Veränderung der Hirnrinde bei Senile Demenz, noted senile plaques, which he called miliary foci, were a specific finding in senile dementia. .	(Amaducci, *et al.,* 1986; Beach, 1987; Berchtold and Cotman, 1998; Berrios, 1995; 2010; Boller, 2008; Boller and Forbes, 1998; Cassanova, *et al.,* 1988; Förstl, 2005; Fukui, 2014; Möller and Graeber, 1998; 2000).
1907	Kraeplin argued arteriosclerotic insanity is not the same as normal senility.	(Beach, 1987).
1907	Fuller also noted the same plaques and tangles as Alzheimer did in several patients of his patients with senile dementia.	(Berrios, 1995; 2010; Förstl, 2005; Ramirez-Bermudez, 2012).
1907	Burr noted that a difficulty in studying mental disease in the aged is distinguishing pathological symptoms from normal changes.	(Holstein, 1997).

1907	Diefendorf sought to separate the physiological changes common to normal senility from milder forms of senile dementia, but decided the line was wholly arbitrary.	(Holstein, 1997).
1908	Bonfiglio, in *Di Speciali Reperti in un Caso di Probabile Sifilide Cerebrale* published the second recorded case of presenile dementia as well as dismissing the idea that miliary foci (senile plaques) are a significant finding in senile dementia.	(Amaducci, *et al.,* 1986; Beach, 1987; Maurer, *et al.,* 2000).
1909	Alzheimer presents his findings before a meeting of the South West German Society of Alienists in Tubingen.	(Fox, *et al.,* 1999).
1909	Persuni, in Uber Klinsch und Histologisch Eigenartige Psychische Erkrankungen des Spärten Lebensalters, reported on 2 cases of pre-senile dementia.	(Beach, 1987; Cipriani, *et al.,* 2011; Maurer, *et al.,* 2000).
1909	Hughes, an American physician blamed morbid vicious indulgences if senile dementia arrived before old age.	(Holstein, 1997).
1910	Kraeplin's naming and use of the term 'Alzheimer-Krankheit' (Alzheimer's disease) in the 8th edition of his *Handbook of Psychiatry*.	(Amaducci, *et al.,* 1986; Ballenger, 2006; Beach, 1987; Berchtold and Cotman, 1998; Berrios, 1995; Berrios, 2010; Cipriani, *et al.,* 2011; Fox, *et al.,* 1999; George, Whitehouse and Ballenger, 2011; Hodges, 2006; Holstein, 1997; Loeb, 1995; Möller and Graeber, 1998; Sachdev, 2000; Ramirez-Bermudez, 2012; Maurer *et al.,* 2000; Möller and Graeber, 2000; Förstl, 2000; Jebelli, 2017).
1910	Southard, in *Anatomical Findings in Senile Dementia: A Diagnostic Study Bearing Especially on the Group of Cerebral Atrophies,* stated that atrophy of the brain was due to arteriosclerosis.	(Beach, 1987; Berrios, 1995; Schwartz and Stark, 1992).

1910	Barrett argued cerebral arteriosclerosis was the cause of senile dementia.	(Beach, 1987).
1910	Fischer noted that plaque-positive cases were a clinical condition he called 'presbyophrenic dementia', differring from simple senile dementia where no plaques occurred.	(Ohry and Buda, 2015)
1911	Alzheimer publishes his second report suggesting that senile dementia can also occur in a younger person.	(Ballenger, 2006; Berrios, 1990; 1995); George, et al., 2011; Möller and Graeber, 1998; Maurer, *et al.,* 2000; Möller and Graeber, 2000).
1911	Persuni, in *Sul Valore Nosografico di Alcumi Reperti Histopatologici Caratteristici per la Senilitá*, casts doubts on Alzheimer's work and confirms senile plaques are a specific finding in senile dementia,	(Amaducci, *et al.,* 1986; Berrios, 1995; Boller, 2008; Boller and Forbes, 1998).
1911	Schnitzler, in *Zur Abgrenzung der Sogenannten Alzheimerschen Erkrankung*, reported on a 31 year old with AD	(Beach, 1987).
1911	Dr Teofil (Tuvia) Simchowicz (1879-1957) coined the term 'senile plaques' in *Histologische Studien über senile Demenz.* He also felt there was evidence to assume an association between neurogenerative changes and dementia and believed AD was only a severe form of senile dementia.	(Berrios, 1995; 2010; Cassanova *et al.,* 1988; Förstl, 2005; Ohry and Buda, 2015).
1911	Nascher (the father of modern geriatrics) described a person with dementia as a 'pilant nonentity'.	(Holstein, 1997).
1911	Fuller found uncomplicated senile dementia, on histological grounds was only an intensification of normal senium	Holstein (1997)
1911	Simchowicz, in *Histologische Studien Ubere die Senile Demenz*, emphasized neuro-fibrillary changes occur in Ammon's Horn (more commonly known today as the hippocampus) of the brain.	(Ohry and Buda, 2015).

1912	Philips, writing in *The Lancet* argued that senile psychosis must be linked to pathological brain change, and not just age.	(Beach, 1987).
1912	Solomon, Fuller and Klopp argued that AD is a distinct form of dementia from senile dementia.	(Beach, 1987; Holstein, 1997).
1912	Wilson, in *Progressive Lenticular Degeneration: a Familial Nervous Disease Associated with Cirrhosis of the Liver,* identified a new form of dementia now known as Wilson's disease.	(Förstl, 2005).
1912	Lewy, in Paralysis Agitans, a chapter in Lewandowsky's *Handbook of Neurology,* discussed his Lewy bodies discovery,	(Förstl, 2005; Fukui, 2014).
1913	Barret, in A Case of Alzheimer's Disease with Unusual Neurological Disturbances, reported the case of a 33 year old with AD.	(Beach, 1987; Berrios, 1995; 2010).
1913	Lewy, in *Zur Pathologischen Anatomie der Paralysis Agitans,* continued his studies in Lewy bodies and presented his findings at the German Association of Psychiatrists and Neurologists.	(Förstl, 2005; Fukui, 2014).
1916	Nascher, founder of the American Geriatrics Movement, in Geriatrics: The diseases of Old Age and their Treatment discussed the pathological process of maturity.	(Beach, 1987).
1916	Byrnes argued cerebral arteriosclerosis was the cause of senile dementia	(Beach, 1987).
1916	Lambert, in *The clinical and anatomical features of AD* argued the underlying pathological features were the same between AD and senile dementia.	(Berrios, 1995; 2010).
1916	Lugaro, in *La psichiatria tedesca nella storia e nell'attualita Rivista di Patologia Nervosa* argued AD is only a variety of senile dementia.	(Berrios, 2010).
1917	Alford argued cerebral arteriosclerosis was the cause of senile dementia.	(Beach, 1987).
1918	Gibson, in *A Clinical Summary of 106 cases of mental Disorder of Unknown Etiology arising in*	(Beach, 1987).

	the Fifth and Sixth Decade defended the use of old age as a classification indicator.	
1919	Konstantin Trétiakoff coined the term “corps de Lewy” meaning ‘Lewy bodies’.	(Fukui, 2014).
1920	Creutzfeldt, in *Ueber eine Eigenartrige Herdfoeminge Erkrankung des Zentralnervensystems*, began his influential work on what would become known as CJD, which leads to a prion form dementia.	(Förstl, 2005; Sachdev, 2000).
1921	Jacob, in *Ueber Eigenartige Erkankungen des Zentrainnervensystem mit Bemerkenertem Anatomischem Befund,* continued the work of Creutzfeldt to look at what would become known as CJD, a prion form of dementia.	(Förstl, 2005; Sachdev, 2000).
1921	Osler and McCrae in *The Principles and Practice of Medicine, 9th Edition* distinguished AD from senile forms of cerebral arteriosclerosis.	(Beach, 1987).
1921	Sterz’s article ‘*Concerning the question of AD’* discussed and questioned the clinicopathology.	(Schwartz and Stark, 1992).
1922	Naville, in *Etudes sure les complications et les sequelles mentales de l’encephalite epidemique: la bradyphrenia*, described the concept of subcortical dementia, calling it ‘bradyphrenia’.	(Albert, 2005; Förstl, 2005).
1922	Hallervoden and Spatz, in *Eigenartige erkrankung im extrapyramidalen system mit besonder beteiligung des globus pallidus und der substantia nigra,* discovered a new dementia now know by their eponym.	(Förstl, 2005).
1922	Gans suggested the eponym ‘Picks Atrophy’.	(Fukui, 2014).
1922	McKeith *et al,* developed the operational criteria for senile dementia of the Lewy Body type (DLB).	(Sachdev, 2000).
1924	Bleuler, in a *Textbook of Psychiatry,* noted that affective disorders can also manifest in subcortical lesions.	(Albert, 2005).

1924	Corrie argued cerebral arteriosclerosis was the cause of senile dementia.	(Beach, 1987).
1924	Gellerstaedt found small numbers of tangles in the majority of normal senile brains.	(Beach, 1987).
1924	Simchowitz, in *Sur la signification des plaques senile et sur la formulr senile de l'écorce cérèbrale*, claimed AD can be differentiated from senile dementia.	(Beach, 1987; Berrios, 1995).
1926	Dr Grünthal, a Polish psychiatrist trained by Kraeplin, in *Uber die Alzheimerische Krankheit* argued the dismissal of cases of AD below age 40 as not being genuine. He also argued the most salient features of Alzheimer's disease included gradual memory loss and disorientation.	(Beach, 1987; Schwartz and Stark, 1992; Jebelli, 2017).
1926	Onari and Spatz suggested the term 'Picksche Krankheit' now known as Pick's disease, a form of fronto-temporal dementia.	(Fukui, 2014; Schwartz and Stark, 1992).
1927	Divry, in *Etude histochimique des plaques séniles* identified the substance at the centre of plaques as 'amyloid' based on Congo red staining techniques.	(Berchtold and Cotman, 1998; Ohry and Buda, 2015).
1927	Binswanger and Siemerling in their *Handbook of Psychiatry* described a range of conditions that could lead to dementia.	(Loeb, 1995).
1927	Schneider's first paper discussing what was recently named 'Picks disease' was published.	(Berrios, 2010).
1928	Cajal proposed that plaques were not purely degenerative and discussed the idea of neuronal sprouting.	(Berchtold and Cotman, 1998).
1929	Malamud and Lowenberg, in *Alzheimer's disease: A contribution to its etiology and classification* dismissed cases that did not contain plaques as not true cases of AD.	(Beach, 1987).
1929	Flügel identified possibility of inheritance in 3 cases of possible AD / Senile dementia.	(Berchtold and Cotman, 1998).
1930	Babcock, in *An experiment in the measurement of mental deterioration* used	(Schwartz and Stark, 1992).

	vocabulary scores as a measure of premorbid intelligence.	
1931	Critchley, writing *The Neurology of Old Age* in *The Lancet* argued that AD can be separated from senile dementia only on clinical grounds, and that pathology was of minimal value.	(Beach, 1987; Berchtold and Cotman, 1998).
1931	Knoll and Ruska invent the electron microscope.	(Boller, 2008).
1932	Von Stockert, in *Subcorticale Demenz* re-labelled bradyphrenia as subcoticale demenz (subcortical dementia).	(Albert, 2005).
1932	Schottky identified familial patterns of dementia inheritance in 2 cases.	(Berchtold and Cotman, 1998; Fox, *et al.,* 1999).
1933	Gellerstaedt reported that over 80% of all non-demented individuals over the age of 65 had some senile plaques and tangles.	(Berchtold and Cotman, 1998; Förstl, 2005).
1933	Introduction of the electron microscope.	(Boller, 2008).
1934	Lowenberg and Waggoner, in *Familial Organic Psychoses (Alzheimer's Type)* identified 5 cases of possible familial/inheritance.	(Berchtold and Cotman, 1998; Hodges, 2006).
1934	Rothschild, in Alzheimer disease: a clinicopathologic study of five cases discussed speech disorder in AD as well as focal deficits.	(Schwartz and Stark, 1992).
1936	Jervis and Soltz argued that only clinical criteria could be used to differentiate AD from senile dementia, not pathology.	(Beach, 1987; Berchtold and Cotman, 1998).
1937	Pritchard's *A Treatise on Insanity* included 4 stages in the clinical course of senile dementia.	(Schwartz and Stark, 1992).
1939	Stern, in *Severe dementia associated with bilateral symmetrical degeneration of the thalamus*, discussed the discovery of the thalamic dementias without signs of atrophy of the red nucleus and chorea.	(Förstl, 2005).
1940	McMenemey argued the presence of 'abundant' plaques and Neurofibrillary tangles is found only in AD and senile dementia.	(Berchtold and Cotman, 1998).

1941	Dr David Rothschild, an American psychiatrist trained in psychoanlayis, with his colleague, argued dementia to be caused by factors of a more personal (rather than biological) nature in *Origin of Senile Psychoses*.	(Ballenger, 2006; Jebelli, 2017)
1944	Mayer-Gross, in *Arteriosclerotic, senile and presenile psychoses* published a symptom list typical of multiple cerebral infarcts associated with vascular dementias.	(Förstl, 2005).
1947	Von Baeyer, in *Zur Pathocharakterologie der organischen Persönlichkeitsveränderungen,* identified Dementia pugilistica	(Förstl, 2005).
1951	APA definition of dementia in *DSM I* as 'organic brain syndromes'.	(Boller and Forbes, 1998; George, *et al.,* 2011).
1954	Greenfield, in *The Spino-Cerebellar Degenerations* discussed growing awareness of the same.	(Förstl, 2005).
1954	Eitinger, a Norwegian Psychiatrist, in *Presenile dementia (Alzheimer's and pick's disease)* provided the first link between AD and the growth of the elderly population.	(Fox *et al.,* 1999).
1954	First published paper to include Alzheimer's disease in its title by Corselis and Brierly.	(Hodges, 2006).
1956	Rothschild, in *Discussion of the article senescence, senility and Alzheimer's disease*, characterised AD as a health and social care problem due to number of older people admitted to public mental hospitals.	(Fox, *et al.,* 1999).
1957	Gajdusek and Zigas, in *Degenerative disease of the central nervous system in New Guinea: the endemic occurrence of "kuru" in the native population*, identified Kuru dementia, a type of prion protein disorder in Papua New Guinea. They were able to link Kuru (which we now know as a type of rare dementia) to pathological findings also found in CJD (also leading to dementia).	(Förstl, 2005).

1957	McCay *et al.,* stitched together pairs of rats, an old rat with a young rat to unite their circulatory system, with the idea of reversing pathological changes in the old mouse by using young blood.	(Jebelli, 2017)
1961	Hirano and Kurland, in *Parkinson-dementia complex, an endemic disease on the island of Guam*, discovered and named Guam-Parkinson-dementia complex.	(Förstl, 2005).
1963	McMenemey, in *Alzheimer's disease: problems concerning its concept and nature,* reviewed the differentiation between AD and senile dementia.	(Berchtold and Cotman, 1998).
1963	Feldman, Chandler, Levy and Glasser discussed the increasing familial incidence of AD.	(Berchtold and Cotman, 1998).
1963	Kidd, in *Paired helical filaments in electron microscopy of Alzheimer's disease,* discovered the paired helical filaments that form tangles using the electron microscope, and the similarities between senile and presenile dementia.	(Boller, 2008; Förstl, 2005).
1964	Albert discussed the similarities between senile and presenile dementia.	(Förstl, 2005).
1964	Terry *et al.,* in *Ultrastructural studies in Alzheimer's presenile dementia*, demonstrated ultrastructural changes in elderly with AD were the same as pre-senile AD.	(Shua-Haim and Ross, 1998).
1966	Martin Roth, a psychiatrist, Bernard Tomlinson, a pathologist and Gary Blessed, another psychiatrist discovered a clear relationship between plaque count and dementia scores in their work *Correlation between scores for dementia and counts of "senile plaques" in cerebral grey matter of elderly subjects.*	(Ballenger, 2006; Berchtold and Cotman, 1998; Boller, 2008; Jebelli, 2017).
1967	Neumann and Cohn, in *Progressive subcortical gliosis – a rare form of presenile*	(Förstl, 2005).

	dementia, discovered a new form of dementia that was without cortical involvement.	
1968	Tomlinson, *et al.,* in *The association between quantitative measures of dementia and senile change in the cerebral grey matter of elderly subjects*, and *Observations on the brains of non-demented old people*, rejected arteriosclerosis as a major cause of dementia.	(Beach, 1987).
1968	Butler used the word 'ageism', arguing mental decline was not a consequence of ageing.	(Ballenger, 2006).
1968	Lauter and Meyer, in *Clinical and nosological concepts of senile dementia,* argued focal signs were common in both presenile and senile cases, and questioned the distinctions between AD and senile dementia.	(Beach, 1987; Schwartz and Stark, 1992).
1968	APA definition of dementia in *DSM II*, including presenile and senile but under the heading psychoses associated with organic brain syndromes.	(Boller and Forbes, 1998; George, *et al.,* 2011).
1969	Olson and Shaw described link between trisomy c21 (Downs syndrome) and AD.	(Hodges, 2006).
1972	Nasu-Hakola, a new form of genetic dementia noted by Hakola, a Finish Physician.	(Manual/own search findings).
1973	McHugh and Folstein, in their address to the American Academy of Neurology (unpub.) linked dementia changes and Huntington's disease, and described these cognitive changes as a subcortical type dementia.	(Boller and Forbes, 1998; Förstl, 2005).
1974	Albert, Feldman and Willis, in *The Subcortical Dementia of Progressive Supranuclear Palsy*, reviewed and updated the concept of subcortical dementia based on patients with PSP.	(Albert, 2005; Boller and Forbes, 1998; Förstl, 2005).
1974	Hachinski, Lassen and Marshall, in *Multi-infarct Dementia: A Cause of Mental Deterioration in the Elderly,* proposed the banishing of the term cerebral arteriosclerosis, instead suggested the term 'multi-infarct	(Beach, 1987; Förstl, 2005).

	dementia', and developed the 'ischaemic score' to identify vascular dementia.	
1974	The National Institute on Ageing (NIA) was established in America.	(Boller, 2008; Fox, *et al.,*1999; Jebelli, 2017).
1974	*Research on Aging Act 1974* passed in America by President Nixon.	(Jebelli, 2017).
1974	David Drachman and Janet Leavitt in, *Human memory and the cholinergic system: a relationship to aging,* found that blocking acetylcholine in young healthy people led to the same memory loss seen in the elderly.	(Jebelli, 2017).
1974	Constantinidis, Richard and Tissot, in *Pick's Disease: Histological and Clinical Correlations* classified Picks Disease into 3 sub-types.	(Fukui, 2014).
1975	McHugh and Folstein, in *Psychiatric Syndromes of Huntington's Chorea: A Clinical and Pharmacological Study*, a book edited by Benson, D. and Blumer, D., updated the concept of subcortical dementia based on patients with Huntington's disease.	(Albert, 2005).
1975	Tissot, Constandtinidis and Richard, based on their previous 1974 findings (Constantinidis, *et al.,*) wrote a clinical text book, *La Maladie du Pick,* that further distinguished 3 different clinic-pathological subgroups of Pick's disease (also known as frontotemporal dementia).	(Förstl, 2005).
1976	Robert Katzman, a physician and scientist, in '*The prevalence and malignancy of Alzheimer's disease'* argued the need to drop the distinction between AD and senile dementia as separate entities.	(Ballenger, 2006; Fox, *et al.,* 1999; Kitwood, 1995; Jebelli, 2017).
1976	Robert Terry, a pathologist, agreed with the findings of Michael Kidd, a physician, that under the microscope the tangles in the brain found in Alzheimer's disease were double-helical in shape, thus importantly differentiating them from plaques in the brain.	(Jebelli, 2017).

1976	Kosaka, *et al.,* in *Pre-senile Dementia with Alzheimer – Pick – and Lewy-body Changes*, reported the first patient with DLB.	(Fukui, 2014).
1977	Katzman, Terry and Bick organised the first AD symposium of the National institute of Health.	(Boller, 2008; Kitwood, 1995).
1977	Isolation of Tau (tublin associated unit) (a micro-tubule associated protein and the main constituent of NFT).	(Boller, 2008).
1977	Perry, *et al.,* in *Necropsy Evidence of Central Deficits in Senile Dementia*, demonstrated cholinergic deficits in senile dementia.	(Förstl, 2005).
1978	Katzman, Terry and Bick – noted AD and senile dementia were the same thing and that it was not part of the normal ageing process.	(Ballenger, 2006),
1978	Hans Selye published his book *The Stress of Life* argued how stress could make us sick.	(Jebelli, 2017)
1979	Founding of the Alzheimer Disease and Related Disease Association.	(Boller, 2008).
1979	Cook, *et al.,* in, *Twins with Alzheimer's Disease*, described autosomal pedigrees of AD.	(Hodges, 2006).
1979	The Alzheimer's Disease Society (known today as the Alzheimer's Society) was formed.	(Jebelli, 2017)
1980	APA definition of dementia published in *DSM III.*	(Boller and Forbes, 1998; George, *et al.,* 2011; Sachdev, 2000).
1980	Butler stated in the *Journal of the American Medical Association* that AD would be used as a term regardless of the age of onset of the disease.	(Shua-Haim and Ross, 1998).
1981	William Summers, a neuroscientist, considered drugs that would bind and stop acetycholinesterase to treat Alzheimer's disease, using tacrine (THA), this was trialed on 12 people with Alzheimer's disease and results published under *'Use of THA in treatment of Alzheimer's-like dementia'*.	(Jebelli, 2017)
1981	Leonard Heston, a physican, and collaegues used 2,000 post-mortem results to show a	(Jebelli, 2017)

	genetic link in early-onset Alzheimer's disease, published as *'Dementia of the Alzheimer type. Clinical genetics, natural history, and associated conditions'*.	
1982	Bondareff, Mountjoy, and Roth expressed doubts about the validity of subcortical dementia.	(Boller and Forbes, 1998).
1982	Mesulam, in *Slowly Progressive Aphasia without Generalised Dementia,* first used the term 'slowly progressive aphasia' for a form of frontotemporal dementia,	(Förstl, 2005).
1982	Barfus, *et al.,* in *The Cholinergic Hypostudy of Geriatric Memory Dysfunction*, elaborated the cholinergic hypostudy of geriatric memory dysfunction.	(Förstl, 2005).
1982	Reisberg *et al.,* developed the GDS (Global Deterioration Scale for Age-Associated Cognitive Decline and Alzheimer's disease).	(Schwartz and Stark, 1992).
1983	Mayeux, *et al.,* argued that subcortical dementia was not a recognisable clinical entity.	(Albert, 2005; Boller and Forbes, 1998).
1984	Creation of the organisation Alzheimer Disease International (ADI).	(Boller, 2008).
1984	NINCDS/ADRDA developed criteria for diagnosing dementia, including AD.	(Boller and Forbes, 1998; Shua-Haim and Ross, 1998).
1984	Glenner and Wong extracted the protein that formed the amyloid plaque and called it beta-amyloid (commonly abbreviated as Aβ). They analysed Aβ deposits, and argued that cerebral Aβ drives AD pathology [now known as the 'amyloid hypostudy], and linked the Aβ to c21 in Downs syndrome. These findings there was a gene for Alzheimer's disease, and a possible 'familial Alzheimer's disease'.	(Tanzi, 2013; Jebelli, 2017)
1985	Masters *et al.,* confirmed and extended the β protein sequence.	(Tanzi, 2013).
1986	Whitehouse challenged the concept of subcortical dementia.	(Boller and Forbes, 1998).
1986	Roth *et al.,* developed CAMDEX	(Sachdev, 2000).

1986	Katzman concluded that AD in presenium and senium ages was the same disease	(Shua-Haim and Ross, 1998).
1986	William Summers developed a tacrine pill (to target acetylcholinesterase) which was trialed on 17 patients. Published as *'Oral tetrahydroaminoacridine in long-term treatment of senile dementia'* it showed how the drug temporarily improved cognition in people with Alzheimer's disease.	(Jebelli, 2017)
1987	APA definition of dementia in *DSM III R*	(Boller and Forbes, 1998; George, Whitehouse and Ballenger, 2011; Sachdev, 2000).
1987	Sucesful decoding of the DNA sequence of beta-amyloid and finding the gene APP (amyloid precursor protein) by several researcher teams: Goldgaber, *et al.,* (1987); Tanzi, *et al.,* (1987); Robakis, *et al.,* (1987); and, Kang, *et al.,* (1987).	(Jebelli, 2017).
1987	McGeer et al., found through post mortem studies that plaques found in people with Alzheimer's disease are often completely surrounded by microglia.	(Jebelli, 2017).
1987	Gustafson defined the clinical criteria for 'frontal lobe degeneration of non-Alzheimer type'.	(Förstl, 2005).
1987	Brun defined the neuropathological criteria for 'frontal lobe degeneration of non-Alzheimer type'	(Förstl, 2005).
1987	St George-Hyslop *et al.,* linked c21 to early onset AD.	(Hodges, 2006).
1987	The term AIDS dementia complex was introduced (now also called neuroAIDS).	(Jebelli, 2017).
1989	Kitwood challenges the biomedical model.	(Bond, 1992).
1989	Bird *et al.* discussed autosomal dominant pedigrees in AD.	(Hodges, 2006).
1990	Cummings – substantiated that subcortical dementias were specific forms of the disease.	(Albert, 2005).

1991	Braak and Braak developed pathological stageing, including tangle formation.	(Hodges, 2006).
1991	Alison Goate, a molecular geneticist, and colleagues found the genetic mutation – a T that should have been a C (single letter of the DNA code on chromosome 21, the APP gene) and with this demonstrated familial AD.	(Hodges, 2006; Shua-Haim and Ross, 1998; Jebelli, 2017).
1991	Hardy and Allsop described c21 gene mutation could lead to an altered APP (linked to AD).	(Shua-Haim and Ross, 1998).
1992	Jack *et al.,* developed sophisticated neuroimageing techniques.	(Hodges, 2006).
1992	John Hardy and a colleague suggested a new theory for the cause of Alzheimer's disease, 'The Amyloid Cascade Hypothesis' – referring to the fact that it is beta-amyloid plaques that first appear (primary event of the disease), with tangles and neurotransmitter loss, cell death and dementia occurring as secondary events.	(Jebelli, 2017).
1992	WHO defined of dementia in *ICD-10.*	(Sachdev, 2000).
1992	Chui, *et al.,* developed the *Criteria for the diagnosis of ischemic vascular dementia proposed by the State of California Alzheimer's disease diagnosis and treatment centers.*	(Sachdev, 2000).
1992	Sabat and Harré questioned the idea of the 'loss of self' in people with dementia.	(Kitwood, 1995).
1992	Kitwood and Bredin argue that stages of dementia re not an ineluctable path.	(Kitwood, 1995).
1993	Tacrine (THA) became the first FDA-approved treatment for Alzheimer's disease.	(Jebelli, 2017).
1993	Three papers published in 1993 (Saunders, *et al.,* Corder, *et. al.,* and Strittmatter, *et al.*) from the Duke ADRC found an association between apolipoprotein E type 4 allele and risk of AD in late onset familial cases. $APOE_4$ carriers have a high risk of Alzheimer's disease. It is present in 30% of the population. It is the leading genetic risk factor.	(Hodges, 2006; Jebelli, 2017).

1993	Hansen *et al.,* discussed the connection between plaque only AD and the LB variant.	(Möller and Graeber, 1998).
1994	APA defined of dementia in *DSM IV.*	(Boller and Forbes, 1998; George, Whitehouse, and Ballenger, 2011; Sachdev, 2000).
1995	Braak and Braak continue their detailed work on pathological stageing.	(Hodges, 2006).
1995	Proof of Hardys theory (see Hardy and Higgins (1992) *op cite.)* by reserachers Games *et al.,* who injecting mice with a human APP gene and they developed brain plaques and cognitive impairement.	(Jebelli, 2017).
1995	Sherrington *et al.,* identified link to c14 in some families with early onset dementia.	(Hodges, 2006).
1995	Maurer *et al.,* find Alzheimer's original 32 page file on his 1906 case	(Maurer, *et al.,* 2000).
1996	Manchester-Lund group called Pick's disease 'frontotemporal lobar degeneration'.	(Fukui, 2014).
1997	Mauer *et al.* published details about the 32 page file by Alzheimer in *The Lancet*.	(Maurer, *et al.,* 2000).
1998	Thomson, a development biologist, and collegues isolated the first human embryonic stem cells – marking the start of a 'regenerative medicine' (opening up possibilities of thought in dementia).	(Jebelli, 2017).
2002	Schenk published his 1997-2000 research findings to find and develop a vaccine (targeting plaques) on animals in the hope of developing a vaccine for Alzheimer's disease. Human trials followed but did not work, causing dangerous side effects.	(Jebelli, 2017).
2003	Based on Schenk's (2002, *op cite.)* work, Hock et al reviewed again the idea of antibodies against plaques.	(Jebelli, 2017).
2003	Terje Lømo, a Norwegian scientist wrote about his work with Per Anderson, which had begun in 1966 on long-term potentiation (LTP) in 'The discovery of long-term potentiation'. The	(Jebelli, 2017).

	model discussed that memories can be made and lost by strengthening and weakening of neuronal synapses.	
2005	Research by Wilson, et al., found a stress prone person is 2.4 times more likely to develop Alzheimer's disease.	(Jebelli, 2017).
2005	Psychiatrists in Dublin (Moran, et al.,) noticed a strong link between sleep disturbances and dementia severity.	(Jebelli, 2017).
2005	Conboy and colleagues at Stanford found that when joining young and old mice, muscle and live tissue in older mice became rejuvenated.	(Jebelli, 2017).
2006	Wilson, et al., repeated his 2005 study (op cite.) and found the risk even higher, a person was 2.7 times now more likely to develop Alzheimers disease if they were a stress prone person.	(Jebelli, 2017).
2006	Takahasi and Yamanaka disovered in mice 4 essential genes that could be used to turn adult cells back into stem cells.	(Jebelli, 2017).
2007	Takashi and colleagues showed how the above (Takahasi and Yamanaka, 2006) could be transferred to humans, coining the term 'induced pluripotent stem' (iPS).	(Jebelli. 2017).
2009	Research (Kang et al.,) found that depriving mice of sllep increases beta-amyloid levels.	(Jebelli, 2017).
2010	Draft APA *DSM 5* suggesting dementia to be characterised as a 'Neurocognitive Disorder'	(George, Whitehouse, and Ballenger, 2011).
2010	Research by Yaffe *et al.,* found that veterans with PTSD were more likely to devlop Alzheimer's disease, supporting link between AD and stress.	(Jebelli, 2017).
2011	Researchers (Erikson, *et al.,*) at the University of Pittsburgh found that exercising 3 days a week produced a 2% increase in hippocampus size in 120 people with an average age of 67.	(Jebelli, 2017).
2011	Villeda and colleagues considered what would happen to the human brain if young blood was	(Jebelli, 2017).

	injected into an older body. Trialed on mice, they found that when young plasma was injected into older mice, the older mice fared much beter in cognitive tests.	
2012	Crammer and colleagues found Bexarotene (a skin cancer drug) could reverse the symptoms of AD in mice.	(Jebelli, 2017).
2013	Stamps and colleagues found that the sense of smell was often lost in people with AD, suggesting a possible test for the disease.	(Jebelli, 2017).
2013	Scott Turner, neurologist, argues that Alzheimer's disease might be detectable in the eye (a much thinner retina). His research was found in mice and was reported at the US Society for Neuroscience Conference, San Diego, November 2013.	(Jebelli, 2017).
2014	Choi, et al., at Harvard University developed an embryonic stem cell culture to replicate Alzheimer's disease. This became known as 'Alzheimer's-in-a-dish'. This meant that links between plaques and tangles on a molecular level coud be studued, aswel as screen more drugs quicker.	(Jebelli, 2017).
2014	Researchers (Mapstone, *et al.,* (2014) at Georgetown University, Washington DC found that differences in the levels of 10 types of blood fats could 'predict' if a person is destined to devlop Alzheimer's disease, three years before symptoms start.	(Jebelli, 2017).
2013	Nedergarrd discovered, in mice, that the brain actually cleans itself during sleeping	(Jebelli, 2017).
2014	Systematic review by Farina et al., found exervise through several methods can have a positive effect in Alzheimner's disease.	(Jebelli, 2017).
2014	Villeda and colleagues continued their research and confirmed that young blood has a powerful affect on memory.	(Jebelli, 2017).

2015	Ariga noted the statistical significance that people who get AD have a lower risk of also getting cancer.	(Jebelli, 2017).
2015	Researchers (Baglietto-Vagras et al., (2015) found that stress might accelerate Alzheimer's disease.	(Jebelli, 2017).
2015	Prion protein researchers from the University College of London provided evidence that beta-amyloid could be transmitted between people.	(Jebelli, 2017).
2015	Researchers in Chicago, Morris *et al.,* found a Meditterranean diet would reduce the risk of Alzheimers disease.	(Jebelli, 2017).
2015	Researchers Nelson and Tablet noted how exercise would slow the progression of Alzheimer's disease.	(Jebelli, 2017).
2015	Researchers at University of California (Mander, *et al.,*) found beta-amloid affects sleep which then also affects memory. This makes sleep a possible therapeutic intervention in Alzheimer's disease.	(Jebelli, 2017).
2016	De Strroper and Karran argues that a cellular theory of AD could be developed.	(Jebelli, 2017).*** (see above)

Appendix 3: The Dementia *Archive*: 2,000 BCE -2016 CE. A 4,000 year history of conceptualising dementia (see Sections 4.3.2 and Section 5.2.1) in 500 documents.

Note: The *Archive* is a product of the findings chapter and is discussed in sections 4.3.2 and 5.2.1 of the study. Some of these documents are referred to explicitly in the study findings, but due to the large number of documents it would not be practical to make reference to all of them.

Ref.	Date	Document
1	2000 BCE	The *Edwin Smith Surgical Papyrus* (1930) [2000 BCE] (trans. Breasted, J.) Chicago: University of Chicago Press.
2	1500 BCE	The *Papyrus Ebers* (1930) [500 BCE approx.] (trans. Bryan), Herts: The Garden City Press Ltd.
3	650 BCE	Writings of Pythagoras's on the division of the life cycle into five climacteric epochs at ages 7, 21, 49, 63 and 81
4	500 BCE	Solon (500 BCE) Known as *Solon's Law* (500 BCE) produced on wooden beams and then later carved into stone [no complete copy of orginal document, just fragments exist. However, Plutarch (75 CE) [trans. Dryden, J.] professes to have seen the original document and provides an account through The Internet Clasics Archives.
5	460 BCE	Writings of Hippocrates on Mental Deterioration, *Prorrhetic I.* In: Potter, P. [1995] (ed.) *Hippocrates*. Cambridge: Harvard University Press.
6	360 BCE	Plato (c.360 BCE) Timaeus. In: Bury, R.G. [1989] (ed.) *Plato, vol. 9.* Cambridge: Cambridge University Press.
7	50 BCE	Lucretius, [full name: Titus Lucretius Carus] (50 BCE) *De rerum natura* [On the nature of things]. (trans. Leonard, W.E.) Reprinted 2007 by Forgotten Books.
8	44 BCE	Cicero (44 BC) *De Senectute* [On old age]. (trans. Peabody, A.) Reprinted 2017.
9	unclear	Galen, C. (1821-1833 translation) De symptomatum differentiis liber. In: Kuhn, C.G. (ed.) *Opera omnia* (Volume 7). Leipzig: Knobloch, pp. 200-201.
10	40 BCE	Horace (40 BC) *Ars Poetica* (trans. Smart, C. and Blankley, E.H. [1928]) Horace on the art of poetry. London: Scholartis Press .
11	100 CE	Celsus (100 AD) *De Medicina* [On medicine]. World Digital Library.

12	1535	Anglicus, B. (1535) *De Proprietatibus Rerum* [On the order of things]. Anton Koberger, 1483.
13	1583	Barrough, P. (1583) Of Memory Lost. In: *The methode of phisicke, conteyning the causes, signes, and cures of inward diseases in man's body from the head to the foote*. London: Vautrollier.
14	1592	Cosin, R. (1592) *Conspiracie, for pretended reformation: viz. presbyteriall discipline*. London: Barker.
15	1599	Laurentius, A.M. (1599) *A discourse on the preservation of the sight; of melancholic diseases; of rheumes, and of old age.* (trans. Andreas, M. and Surphlet, R.) Shakespear Association Facsimiles No. 15.
17	1656	Fernel, J. (1656) *Universal Medicina*, lib III, cap III. Utrecht: à Ziyll and van Ackersdijck.
18	1672	Schneider, C.V. (1672) *Liber de Nova Gravissimorum Trium Morborum Curatione, de Apoplexia, Lipopsychia, Paralysi.* Frankfurt: Bakium.
19	1672	Willis, T. (1672) *De Anima Brutorum quae Hominis Vitalis ac Sensitiva est.* London: Davis.
20	1726	Blancard, S. (1726) *The physical dictionary wherein the terms of anatomy, the names and causes of diseases, chirurgical instruments and their use are accurately described.* London: John and Benjamin Sprint.
21	1751	Boerhaave, H. (1751) Praelectiones academicae. In: Von Haller, A. (ed.) Volume 3. Venice.
22	1754	Diderot and d 'Alembert (eds.) (1754) *Encyclopdédie ou dictionnairé raisonne des Sciences, des Arts et des Maitières par une Société de Gens de Lettres*. Paris: Briasson, David, Le Breton and Durand.
23	1763	von Haller, A. (1763) *Elementa physiologiae corporis humani.* Lib XVII, sec I. Vol 5. Lusanne.
24	1772	Boissier de Sauvages, F. (1772) *Nosologia Metodica Morborum Classes*. N Pezzana: Venetiis.
25	1793	Cullen, W. (1793) *A Synopsis of Medical Nosology.* Philadelphia: Hall.
26	1793	Rush, B. (1793) *An account of the state of mind and body in old age; with observations on its diseases, and their remedies.* Reprinted as 'On old age,' In: Runes, D.V. (ed.) *Selected writings of Benjamin Rush.* New York: Philosophical Press.

27	1801	Pinel P (1801) Traité Médico-Philosophique sur l'Aliénation Mentale, ou la Maine. Paris: Richard, Caille and Ravier (trans. Davis, D.D. [1962]) *A Treatise on Insanity*, New York: Hafner.
28	1805	Esquirol, E. (1805) *Des Passions.* Paris: Didot Jeune.
29	1811	Jameson, T. (1811) *Essays on the changes of the changes of the human body and its different ages.* London: Longman.
30	1816	Pinel, F. (1816) *Nosografia filosofica o il metedo dell'analisi applicator alla medicina* (traduz). IV ed. Frances) F. Abbate Qm. Domenico: Palermo.
31	1822	Bayle, L.J. (1822) *Recherches sur les maladies mentales.* Paris: Gabon et Compagnie.
32	1829	Esquire, J. (1829) *Della Alienazione Mentale o della Pazzia in genere e in ispecie*. Milano: Felice Rusconi.
33	1832	Elliotson, J. (1832) St Vitus's dance. *Lancet,* i:162-165.
34	1834	Combe, A. (1834) *Observations on mental derangement.* (facsimile reproduction of the first American edition [1972]). Delmar NY: Scholars Facsimiles and Reprints.
35	1837	Prichard, J.C. (1837) *A treatise on insanity and other disorders affecting the mind*. Philadelphia: Has well, Barrinton and Has well.
36	1838	Esquirol, J.E.D. (1838) *Traité des Maladies Mentales.* Paris: Bailliere. (trans. Hunt, E.K. [1845]) Mental Maladies – a treatise on insanity. Philadelphia: Lea and Blanchard.
37	1839	Morrison, A. (1839) *The physiognomy of mental diseases*. (2nd ed.) London: British Library facsimile.
38	1842	Dunglison, R. (1842) *The practice of medicine*. Philadelphia: Lee and Blanchard.
39	1849	Day, G.E. (1849) *Practical treatise on the domestic management and most important diseases of advanced life*. London: Lea Boone.
40	1854	Winslow, F. (1854) Lettsomiam lectures in insanity. London: John Churchill.
41	1855	Wood, G.B. (1855) A treatise on the practice of medicine. Philadelphia: Lippincott.

42	1859	Virchow, R. (1858) *Die celulapathologie in ihrer Bergündung auf physiologische und pathologische Gewebelehre.* Berlin: Verlag von August Hirschwald.
43	1860	Morel, B.A. (1860) *Traités des Maladies Mentales.* Paris: Mason.
44	1863	Lyon, I.W. (1863) Chronic hereditary chorea. *American Medical Times,* 7:289-290.
45	1863	Marcé, L.V. (1863) Recherches cliniques et anayomo-pathologiques sur la démence senile et sur les differences que la séparent de la paralysie general. E Thumoret C:11-27.
46	1867	Charcot, J.M. (1867) *Lécons sur les Maladies des Viellards et les Maladies Chroniques*. Paris (trans. Tuke, W.S. [1881] *Clinical lectures on senile and chronic diseases.* London: New Sydenham Society.
47	1873	Sheppard, E. (1873) *Lectures on madness in its medical, legal and social aspects.* London: J Churchill, A Churchill
48	1874	Beard, G.M. (1874) *Legal responsibility in old age: based on researches into the relation of age to work.* New York: Russell's American Steam Printing House.
49	1874	Wernicke, C. (1874) *The aphasia symptom complex; a psychological study on an anatomical basis.* In: Eggert, G.H. (ed. and trans.), [reprint 1977], *Wernicke's works on aphasia*. The Hague: Mouton.
50	1876	Griesimger, W. (1876) *Die Pathologie und therapie der psychischen Krankheiten.* 4a Ed. Braunschweig.
51	1880	Maudsley, H. (1880) *The Pathology of Mind.* New York: Appelton.
52	1881	Ball, B. and Chambard, E. (1881) Démence apoplectique. In: Dechambre, A. and Lereboullet, L. (eds.) *Dictionaire encyclopedique des sciences medicales.* Paris: Masson.
53	1881	Charcot, J.M. (1881) *Clinical lectures on senile and chronic diseases* (trans. Tuke, W.S.). London: New Sydenham Society.
54	1881	Charcot, J.M. and Loomis, A.L. (1881) *Clinical lectures on the diseases of old age.* New York: William Wood.
55	1881	Wernicke, C. (1881) Lehrbuch der gehirnkrankheiten (Vol. II) Kassel: Fischer.
56	1885	Lichtheim, L. (1885) On aphasia. *Brain,* 2:433-484.

57	1885	Meynert, T. (1885) *Psychiatry: A clinical Treatise on diseases of the forebrain based on its structure, function and nutrition.* Part 1. New York: G.P. Putnam and Sons.
58	1887	Huber, A. (1887) Chorea hereditaria der Erwachsenen (Huntingtonsche Chorea). *Virchows Archiv für Pathologische Anatomie,* 108:267-285.
59	1887	Hughes, C. (1887) Insanity defined on the basis of disease. *The Alienist and Neurologist,* 20:170-174.
60	1887	Korsakov, S.S. (1887) *Ob Alkoholnom Paralichie*. Moscow: Kushnereff.
61	1890	Lissauer, H. (1890) Ein fal von seelenblindheit nebst einem beiträge zur theorie der selben. *Archivr für Psychiatrie und Nervenkrankheiten,* 21:222-270.
62	1892	Blocq, P. and Marienesco, G. (1892) Sur les lesions et la pathogéne l'épilepsie dite essentielle. *Semaine Medical,* 12:44-446.
63	1892	Dejerine, J. (1892) Contribution a l'étude anatomoclinique et clinique des différentes varieties de cécité verbale. *Compte rendu hebdomadaire des scénances et memoires de la société de biologie,* 4:61-90.
64	1892	Pick, A. (1892) Uber die beziehungen der senilen hirnatrophie zur aphasie. *Prgaer Medicinische Wochenschrift,* 14:403-404.
65	1893	Binswanger, O. (1893) *Die pathologische histologie der grosshirnrinden-erkrankung bei der Allgemeinen Progressiven Paralyse.* Jena, Germany: Gustav Fischer.
66	1894	Alzheimer, A. (1894) Die arteriosklerotische atrophie des gehirns. *Neurologisches Zentralblatt,* 13:765-768.
67	1894	Binswanger, O. (1894) Die abgrenzung der allgemein progressive paralyze. *Berl. Klin. Wochenscher,* 31:1103-1105, 1180-1186.
68	1895	Mercier, C. (1895) *Sanity and insanity*. Walter Scott: London.
69	1897	Clarke, J.M. (1897) On Huntingtin's chorea. *Brain,*1: 22-34.
70	1898	Alzheimer, A. (1998) Neuere Arbeiten über die Dementia senilis und die auf atheromatöser Gefässerkrankung basierenden Gehirnkrankheiten. *Monatsschrift für Psychiatrie und Neurologie,* 3:101-115.
71	1898	Clouston, T.S. (1898) Mental Diseases. (5th ed.) London: Churchill.

72	1898	Redlich, E. (1898) Ueber miliare sklerose der hirnrinde bei senile atrophie. *Jahrbucher für Psychiatrie und Neurologie,* 17:208-216.
73	1899	Alzheimer, A. (1899) Beitrag zur pathologischen anatomie der seelenströrungen des greisenalters. *Neurol Zentralblatt,* 18:95-96.
74	1899	Kraepelin, E. (1899) *Compendium der psychiatrie,* (6th ed.) Lepzig: Abel.
75	1900	Flechsig, P. (1900) über Projections- und Associations-Zentren des menschlichen Gehirns [On projection and association centres of the human brain]. *Neurologie Zentralblatt,* 19.
76	1902	Alzheimer, A. (1902) Die seelenströrungen auf arteriosklerotischer grundlage. *Allgemeine Zeitschrift fur Psychiatrie und psychisch-gerichtliche Medicin,* 59:695-711.
77	1902	Gowers, W.B. (1902) Abiotrophy. *Lancet,* 1:1003-1007.
78	1902	Alzheimer, A. (1902) Die seelenstörungen auf arterioklerotischer grundlage. *Allgemeine Zeitschrift für Psychiatrie,* 59:695-710.
79	1902	Russell, W. (1902) Senility and senile dementia. *American Journal of Insanity,* 59:625-633.
80	1903	Pickett, W. (1903) Senile dementia: A clinical study of two hundred cases with particular regard to types of the disease. *Transactions of the Philadelphia Neurological Society.* April 28.
81	1904	Canguilhem, G. (1904) *The Normal and the Pathological.* (trans. Fawcett, C.R. [1991]). New York: Zone Books.
82	1904	Kraeplin, E. (1904) *Lehrbuch der psychiatrie.* (7th ed.) Lepzig: Barth (trans. Diefendorf, A.R. [1912] *Clinical psychiatry.* New York: MacMillan.
83	1904	Pickett, W. (1904) Senile dementia: A clinical study of two hundred cases with particular regard to types of the disease. *Journal of Nervous and Mental Diseases,* 31:81-88.
84	1904	Spearman, C. (1904) General intelligence objectively determined and measured. *American Journal of Psychology,* 15:201-293.
85	1905	Bolton, J.S. (1905) Amentia and dementia: a clinic-pathological study. *Journal of Mental Science,* 51:270-336.
86	1905	Liepmann, H. (1905) Die Linke Hemisphäre und das Handeln. *Münch Med Wschr,* 49:2375-2378.

87	1906	Pick, A. (1906) Ueber einen weiteren Symptomenkonmplex im Rahmen der Dementia senilis, bedingt durch umschriebene, stärkere Hirnatrophie (gemischte Apraxie). *Fahrbuch der Psychiatrie und Neurologie,* 19:97-108.
88	1907	Alzheimer, A. (1907) Über eine eigenartige Erkrankung der Hirnrinde. *Allgemeine Zeitschrift für Psychiatrie.* 64:146-148 (trans. Hochberg, C.N. and Hochberg, F.H. (1977) A unique illness involving the cerebral cortex. In: Rothenberg, D.A. and Hochberg, F.H. (eds.) *Neurological Classics in Modern Translation.* New York: Hafner,
89	1907	Fischer, O. (1907) Miliäre Nekrosen mit drusigen Wucherungen der Neurofibrillen, eine regelmässige Veränderung der Hirnrinde bei senile Demenz. *Monatsschrift für Psychatrie und Neurologie.* 22:361-372.
90	1908	Fischer, O. (1908) Die histopathologie de presbyophrenie. Silzungsbericht deutsch. *Verein Psych Allg Zeitschr f Psych.* 65:500.
91	1908	Bonfiglio, F. (1908) Di speciali reperti in un caso di probabile sifilide cerebrale. *Rivista Sperimentale di Freniatria.* 34:196-206.
92	1909	Opprenheim, G. (1909) Ueber “drusige nekrosen” in der groshirnrinde. *Neurol Centralbl,* 28:410.
93	1909	Perusini, G. (1909) Über klinisch und histologisch eigenartige psychische Erkrankungen des späteren Lebensalters. In: Nissl, F. and Alzheimer, A. (eds.) Histologische und histopathologische Arbeiten. Jena: Verlag G Fischer. pp.297-351.
94	1910	Vedrani, A. (1910) *Le placche di Fischer.* II Bollettinodei Manicomi: Fasc 7.
95	1910	Kraeplin, E. (1910) Psychiatrie: ein lehrbuch für studierende und Ärzte, vol 2. *Klinishe Psychiatrie,* part 1. (8th ed.) Leipzig: Barth.
96	1910	McGaffin, C.G. (1910) An anatomical analysis of seventy cases of senile dementia. *American Journal of Insanity,* 65:649-656.
97	1910	Perusini, G. (1910) Über klinisch und histologisch eigenartige psychische Erkrankungen des späteren Lebensalters. *Histologische und Histopathologische Arbeiten über die Grossshirnrinde,* 3:297- 358.
98	1910	Southard, E.E. (1910) Anatomical findings in senile dementia: A diagnostic study bearing especially on the group of cerebral atrophies. *American Journal of Insanity,* 66:693-708.

99	1911	Alzheimer, A. (1911) Uber eigenartige krankheitsfalle des spateren *Alters. Z. Neurol. Psychiat.,* 4:356-385.
100	1911	Clouston, T.S. (1911) *The unsoundness of mind.* New York: Dutton.
101	1911	Barrett, A.M. (1911) Degeneration of intracellular neurofibrils with military gliosis in psychosis of the senile period. *American Journal of Insanity,* 57:503.
102	1911	Nascher, I. (1911) Senile mentality. *International Clinics,* 4:48-59.
103	1911	Simchowicz, T. (1911) Histologische studien uber die senile demenz. In: Nissl, F. and Alzheimer, A. (eds.). *Histologische und histopathologische arbeiten über die grosshirnrinde mit besonderer berücksichtigung der pathologischen anatomie der geistekrankheiten*. Jena: Fischer Verlag, 4: 267-444.
104	1911	Perusini, G. (1911) Sul valore nosografico di alcumi reperti histopatologici caratteristici per la senilità. *Rivista Italiana di Neuropatologia, Psichiatria ed Elettroterapia,* 4:145-213.
105	1911	Schnitzler, J.G. (1911) Zur abgrenzung der sogenannten Alzheimerschen Erkrankung. *Ztschr. Neurol. Psychiatr.,* 7:34-37.
106	1912	Courbon (D'Amiens) (1912) Intégrité de la mémoire et démence. *Rev. Psychiatr.,* 16:448-455.
107	1912	Fuller, S.C. and Klopp, H.I. (1912) Further observations on Alzheimer disease. *American Journal of Insanity,* 69:17-29.
108	1912	Fuller, S.C. (1912) Alzheimer's disease (senium praecox): the report of a case and review of published cases. *Journal of Nervous and Mental Diseases,* 39:440-536.
109	1912	Lewy, F.H. (1912) Paralysis agitans. I. Pathologische Anatomie. In: Lewandowsky, M. (ed.) *Handbuch der Neurologie,* (Vol. III). Berlin: Springer, pp.920-933.
110	1912	Wilson, S.A.K. (1912) Progressive lenticular degeneration: a familial nervous disease associated with cirrhosis of the liver. *Brain,* 34:295-309.
111	1913	Barrett, A.M. (1913) A case of Alzheimer's disease with unusual neurological disturbances. *Journal of Nervous and Mental Diseases,* 40:361-374.

112	1913	Byrnes, C.M. (1913) A clinical and pathological study of a condition occurring in the aged usually attributed to cerebral arteriosclerosis. *Journal of Nervous and Mental Diseases,* 43:489-504.
113	1913	Lewy, F.H. (1913) Zur pathologischen Anatomie der Paralysis agitans. *Deutsche Zeitschrift für Nervenheilkunde,* 50:50-55.
114	1913	Mingazzini, G. (1913) On aphasia due to atrophy of the cerebral convolutions. *Brain,* 36:493-524.
115	1914	Nascher, I.L. (1914) *Geriatrics: The diseases of old age and their treatment.* Philadelphia: Blakiston.
116	1914	Sig, E. (1914) Versuch einer retrospektiven diagnostic der senilen psychosen nach dem drusenbefund. *Zeitschr. Neurol. Psych.,* 24:453.
117	1915	Nascher, I.L. (1915) Evidences of senile impairment. *American Journal of Clinical Medicine,* 22:544 - 449.
118	1916	Nascher, I.L. (1916) Geriatrics: The diseases of old age and their treatment. Philadelphia: Blakiston.
119	1918	Gibson, E.T. (1918) A clinical summary of 10 cases of mental disorder of unknown etiology arising in the fifth and sixth decade. *American Journal of Insanity,* 75: 221-249.
120	1918	Kraeplin, E. (1918) Hundert Jahre Psychiatrie. Berlin: Julius Springer Verlag (trans. Baskin, W. (1962) *One hundred years of psychiatry*). New York: Philosophical Library.
121	1920	Creutzfeldt, H.G. (1920) Ueber eine eigenartrige herdfoerminge Erkrankung des Zentralnervensystems. *Zeitschrift für die Gesamte Neurolie und Psychiatrie*, 57:1-18.
122	1920	Flechsig, P. (1920) *Anatomie des menschlichen Gehirns und Rückenmarks auf myelogenetischer Grundlage.* Lepzig: Thieme.
123	1920	Liepmann, H. (1920) Apraxie. *Ergon der ges Med,* 1:516-543.
124	1921	Jacob, A. (1921) Ueber eigenartige erkrankungen des Zentralnervensystem mit bemerkenertem anatomischem Befund (spastiche Pseudosclerose- Encephalomyelopathie mit disseminierten Degenerationsherden). *Deutsche Zeitschrift für Nervenheilkunde,* 70:132-138.
125	1921	Osler, W. and McCrae, T. (1921) *The Principles and Practice of Medicine*. (9th ed.) New York: Appelton.

126	1921	Stertz, G. (1921) *Der extrapyramidale Symptomenkomplex (das dystonische Syndrom) und seine Bedeutung in der Neurologie.* Berlin: Krager.
127	1922	Hallervoden, J. and Spatz, H. (1922) Eigenartige erkrankung im extrapyramidalen system mit besonder beteiligung des globus pallidus und der substantia nigra. *Zeitschrift für die Gesante Neurologie*, 79:254.
128	1922	Naville, F. (1922) Etudes sure les complications et les sequelles mentales de l'encephalite epidemique: la bradyphrenie. *L'Encephale,* 17:369-375.
129	1924	Bleuler, E. (1924) Textbook of Psychiatry. (trans. Brill, A.A.) New York: MacMillan Co.
130	1924	Simchowitz, T. (1924) Sur la signification des plaques senile et sur la formule senile de l'écorce cérèbrale. *Rev. Neurol.,* 31,Pt 1:221-227.
131	1926	Grünthal, E. (1926) Über die Alzheimerische Krankheit. Ztschr. *Neurology and Psychiatry,* 101:128-157.
132	1927	Divry, P. (1927) Étude histochimique des plaques séniles. *Journal Belge de Neurologie et Psychiatrie*, 9:643-657.
133	1927	Spearman, C. (1927) *The abilities of man*. New York: MacMillan.
134	1929	Kotsovsky, D. (1929) The origin of senility. *American Journal of physiology,* 90:419-420.
135	1929	Malamud, W. and Lowenberg, K. (1929) Alzheimer's disease: A contribution to its etiology and classification. *Archives of Neurology and Psychiatry,* 21:805-827.
136	1930	Babcock, H. (1930) *An experiment in the measurement of mental deterioration. Archives in Psychology,* 18:5-105.
137	1931	Critchley, M. (1931) The neurology of old age, part III. *The Lancet,* I:1331-1337.
138	1932	Von Stockert, F.G. (1932) Subcorticale Demenz. *Archiv für Psychiatrie,* 97:77-100.
139	1934	Lowenberg, K. and Waggoner, R. (1934) Familial organic psychoses (Alzheimer's type). *Archives of Neurology and Psychiatry,* 31:737-754.
140	1934	Rothschild, D. (1934) Alzheimer's disease: a clinicopathologic study of five cases. *American Journal of Psychiatry,* 91:485-519.

141	1936	Hannah, J.A. (1936) Case of Alzheimer's disease with neuropathological findings. *Canadian Medical Association Journal,* 35:361-366.
142	1936	Rothschild, D. and Kasanin, J. (1936) Clinicopathic study of Alzheimer's disease: relationship to senile condition. *Archives of Neurology and Psychiatry,* 3:293-321.
143	1938	Du Laurens, A. (1938) A discourse of the preservation of sight: Of melancholike diseases; of rheumes and of old age. (trans. Surphlet, R.) London: The Shakespeare Association.
144	1939	Stern, K. (1939) Severe dementia associated with bilateral symmetrical degeneration of the thalamus. *Brain,* 62:157-171.
145	1944	Mayer-Gross, W.A. (1944) Arteriosclerotic, senile and presenile psychoses. *Journal of Mental Science,* 1:316-327.
146	1947	Von Baeyer, W. (1947) Zur Pathocharakterologie der organischen Persönlichkeitsveränderungen. *Nervenarzt,* 178:21-28.
147	1947	Christian, H.A. (1947) *The principles and practice of medicine,* (16th ed.) New York: Appelton.
148	1948	World Health Organisation (1949) *Manual of the International Classification of Diseases, Injuries, and Causes of Death (ICD-6).* Geneva: WHO.
149	1949	Sjögren, T. (1950) Hereditary congenital spinocerebellar ataxia accompanied by congenital cataract and oligophrenia. *Confinia Neurologica,* 10:293-308.
150	1950	Botwinick, J. and Birren, J.E. (1951) Differential decline in the Wechsler-Bellevue subtests in the senile psychoses. *Journal of Gerontology,* 6:365-368.
151	1951	American Psychiatric Association (1952) *Diagnostic and Statistical Manual of Mental Disorders (DSM-I).* Washington DC: APA.
152	1952	Fink, M., Green, M.A. and Bender, M.B. (1952) The Face-Hand test as a sign of organic mental syndrome. *Neurology,* 1:46-58.
153	1953	Roth, M. and Hopkins, B. (1953) Psychological test performance in patients over 60. I. Senile psychosis and the affective disorders of old age. *Journal of Mental Science,* 99:439.

154	1954	Eitinger, L. (1954) Presenile dementia (Alzheimer's and Pick's disease). *Acta Psychiatr Neurol Scand,* 29:411-421.
155	1954	Greenfield, J.G. (1954) *The Spino-Cerebellar Degenerations*. Oxford: Blackwell.
156	1956	Rothschild, D. (1956) Discussion of the article senescence, senility and Alzheimer's disease. *American Journal of Psychiatry,* 113:133-137.
157	1957	Gajdusek, D.C. and Zigas, V. (1957) Degenerative disease of the central nervous system in New Guinea; the endemic occurrence of "kuru" in the native population. *New England Journal of Medicine,* 257:974-948.
158	1958	Mutrux, S. (1958) Contribution a l'étude histologique differentielle de la démence senile et de la maladie à Alzheimer. *European Neurology,* 136(3):146-156.
159	1958	Reitan, R.M. (1958) Validity of the trail making test as an indicator of organic brain damage. *Perceptual and Motor Skills,* 8:271-271.
160	1959	Hadlow, W.J. (1959) Scrapie and kuru. *Lancet ii*: 289-290.
161	1959	Margolia, G. (1959) Senile cerebral disease: a critical survey of traditional concepts based upon observations with newer technics. *Laboratary Investigation,* 8:335-370.
162	1960	Kahn, R.L., *et al.,* (1960) Brief objective measures for the determination of mental status in the aged. *American Journal of Psychiatry,* 117:326-328.
163	1961	Hirano, A. and Kurland, L.T. (1961) Parkinson-dementia complex, an endemic disease on the island of Guam. *Brain,* 84:642-679.
164	1962	Kral, V.A. (1962) Senescent forgetfulness: Benign and malignant. *Canadian Medical Association Journal,* 86(6):257-260.
165	1963	Katz, S., *et al.,* (1963) Studies of illness in the aged. The index of ADL: A standardized measure of biological and psychosocial function. *Journal of the Medical Association,* 185:914-919.
166	1963	McMenemy, W.H. (1963) Alzheimer's disease: Problems concerning its concept and nature. *Acta Neurol Scand,* 39:369-380.
167	1963	McMenemy, W.H. (1963) The dementias and progressive diseases of the basal ganglia. In: Blackwood, W., McMenemy, W.H., Meyer, A. and

		Norman, R.M. (eds.) *Greenfield's neuropathology,* (2nd ed.) London: Arnold, pp. 520-580.
168	1963	Kidd, M. (1963) Paired helical filaments in electron microscopy of Alzheimer's disease. *Nature,* 197:192-193.
169	1963	Richardson, J.C., Steele, J.C. and Olszewski, J. (1963) Supranuclear opthalmoplegia, pseudobulbar palsy, nuchal dystonia and dementia. *Transactions of the American Neurological Association,* 88:25-27.
170	1964	Terry, R.D., Gonatas, N.K. and Weiss, M. (1964) Ultrastructural studies in Alzheimer's presenile dementia. *American Journal of Pathology,* 44: 269-297
171	1964	Zangwill, O.L. (1964) Psychopathology of Dementia. *Proceedings of the Royal Society of Medicine,* 57:914-917.
172	1966	Bacon, R. (1966) *De retardation accidentum senectutis.* Hants: Gregg.
173	1967	Neuman, M.A. and Cohen, R. (1967) Progressive subcortical gliosis – a rare form of presenile dementia. **Brian,** 90:405-418.
174	1967	Plutarch (trans.) (1967). *Plutarch: Lives.* New York: AM Press.
175	1967	World Health Organisation (1967) *Manual of the International Classification of Diseases, Injuries, and Causes of Death* (ICD-8). Geneva: WHO.
176	1968	American Psychiatric Association (1968) *Diagnostic and Statistical Manual of Mental Disorders, DSM-II.* (2nd ed.) Washington DC: APA
177	1968	Blessed, G., Tomlinson, B.E. and Roth, M. (1968) The association between quantitative measures of dementia and senile change in the cerebral grey matter of elderly subjects. *British Journal of Psychiatry*, 114:797-811.
178	1968	Lauter, H. and Meyer, J.E. (1968) Clinical and Nosological Concepts of Senile Dementia. In: Müller, C. and Ciompi, L. (eds.) *Senile dementia.* Bern Stuggart: Huber, pp.13-26.
179	1968	Rebeiz, J., Kolodney, E. and Richardson, E. (1968) Corticodentatonigral degeneration with neuronal achromatasia. *Archives of Neurology,* 18: 20-33.
180	1968	Tomlinson, B.F., Blessed, G. and Roth, M. (1968) observations on the brains of non-demented old people. *Journal of the Neurological Sciences*, 7:331-356.

181	1969	Wilkins, R.H. and Brody, I.A. (1969) Alzheimer's Disease. *Archives of Neurology,* 21:109-111.
182	1971	Deutsch, J.A. (1971) The cholinergic synapse and the site of memory. *Science,* 174:788-794.
183	1972	Hodkinson, M. (1972) Evaluation of a mental test score for assessment of mental impairment in the elderly. *Age and Ageing,* 1:233-238.
184	1972	Isaacs B and Akhtar A (1972) The SET Test: a rapid test of mental function in old people. *Age and Ageing,* **1**: 222-226
185	1973	Buschke, H, (1973) Selective reminding for analysis of memory and learning. *Journal of Verbal Learning and Verbal Behaviour,* 12:543-550
186	1973	McHugh, P.R. and Folstein, M.F. (1973) Address to the American academy of neurology, recent advances in dementia (unpubl.) Cited in McHugh, P.R. and Folstein, M.F. (1975) Psychiatric symptoms of Huntington's chorea – a clinical and phenomenologic study. In: Benson, D.F. and Blumer, D. (eds.) (1975) *Psychiatric aspects of neurologic disease.* New York: Grune and Straton, pp.267-286.
187	1974	Albert, M.L., Feldman, R.G. and Willis, A.L. (1974) The 'subcortical dementia' of progressive supranuclear palsy. *Journal of Neurology, Neurosurgery and Psychiatry,* 37(2):121-130.
188	1974	Hachinski, V.C., Lassen, N.A. and Marshall, J. (1974) Multi-infarct dementia: a cause of mental deterioration in the elderly. *Lancet,* ii: 207-210.
189	1974	Drachman, D.A. and Leavitt, J. (1974) Human memory and the cholinergic system. A relationship to ageing? *Archives of Neurology,* 30:113-121.
190	1974	Shader, R.I., Harmaty, J.S. and Salzmann, C. (1974) A new scale for clinical assessment in geriatric populations: Sandoz clinical assessment-geriatric (SCAG). *Journal of the American Geriatrics Society*, 22:107-113.
191	1974	World Health Organisation (1974) *Glossary of the Mental Disorders and Guide to their Classification, for use in conjunction with the international classification of diseases,* 8th revision. Geneva: WHO.

192	1975	Katzman, R. and Karasu, K. (1975) Differential diagnosis of dementia. In: Fields, W. (ed.) *Neurological and sensory disorders in the elderly.* New York: Stratton Intercontinental Medical Book Corp.
193	1975	McHugh, P. and Folstein, M. (1975) Psychiatric syndromes of Huntington's chorea: a clinical and pharmalogical study. In: Benson, D. and Blumer, D. (eds.) *Psychiatric aspects of neurologic disease.* New York: Grune and Stratton.
194	1975	Tissot, R., Constantinidis, J. and Richard, J. (1975) *La maladie du Pick.* Paris: Masson.
195	1975	Folstein, M.F., *et al.,* (1975) Mini-mental state: A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research,* 12:189-198.
196	1976	Davies, P. and Maloney, A.J.R. (1976) Selective loss of central cholinergic neurons in Alzheimer's disease. *Lancet,* II:1403.
197	1976	Katzman, R. (1976) The prevalence and malignancy of Alzheimer disease. *Arch. Neurol,* 33:217-218.
198	1976	Mattis, S. (1976) Mental status examination for organic mental syndrome in the elderly patient. In: Bellak, L. and Karasu, T. (eds.), *Geriatric Psychiatry: a handbook for psychiatrists and primary care physicians.* New York: Grune and Stratton, pp. 77-101.
199	1976	Roberts, M.A., *et al.,* (1976) Computerized tomography in the diagnosis of cerebral atrophy. *J Neurol Neurosurg Psychiatry,* 39:905-915.
200	1977	Jacobs, J.W., *et al.,* (1977) Screening for organic mental syndromes in the medically ill. *Annals of Internal Medicine,* 86:40-46.
201	1977	Medical Research Council (1977) *Senile and Presenile dementia: a report of the MRC subcommittee,* compiled by Lishman, W.A. London: MRC.
202	1977	Terry, R.D., *et al.,* (1977) Cortical cell counts in senile dementia. *Journal of Neuropathololology and Experimental Neurology*, 36(3):633.
203	1977	Perry, E.K., *et al.,* (1977) Necropsy evidence of central cholinergic deficits in senile dementia. *Lancet,* 1(8004): 189.
204	1977	Walton, J.N. (1977) *Brain's Diseases of the Nervous System.* New York: Oxford University Press.

205	1977	World Health Organisation (1977) *Manual of the International Statistical Classification of Diseases, Injuries and Causes of Death,* 9th rev. Geneva: WHO.
206	1978	Hare, M. (1978) Clinical checklist for diagnosis of dementia. *British Medical Journal,* 2:266-267.
207	1978	Torack, R.M. (1978) *The Pathologic Physiology of Dementia, with Indications for Diagnosis and Treatment.* Berlin: Springer-Verlag.
208	1978	Roth, M. (1978) Diagnosis of senile and related forms of dementia. In: Katzman, R., *et al.,* (ed.) *Alzheimer's disease: Senile dementia and related disorders.* New York: Raven Press, pp.71-85.
209	1978	Katzman, R., Terry, R. and Bick, K. (1978) *Alzheimer's disease: senile dementia and related disorders.* New York: Raven Press.
210	1978	Kral, V.A. (1978) Benign senescent forgetfulness. *Ageing NY,* 7:47-51.
211	1978	Terry, R.D. (1978) Ageing, senile dementia, and Alzheimer's disease. *Ageing NY,* 7:11-14.
212	1978	World Health Organisation (1978) *Mental Disorders: glossary and guide to their classification in accordance with the ninth revision of the international classification of disease.* Geneva: WHO.
213	1979	Torack, R.M. (1979) Adult dementia: history, biopsy, pathology. *Neurosurgery,* 4:432-434.
214	1979	De Leon, M.J., *et al.,* (1979) Correlations between computerized tomographic changes and behavioural deficits in senile dementia. *Lancet,* 2(8147):859-860.
215	1979	Pattie, A.H. and Gilleard, C.J. (1979) Manual of the Clifton Assessment Procedures for the Elderly (CAPE). Sevenoaks: Hodder and Stoughton Educational.
216	1980	American Psychiatric Association (1980) *Diagnostic and Statistical Manual of Mental Disorders (DSM-III).* 3rd ed. Washington DC: APA.
217	1980	De Leon, M.J., *et al.,* (1980) Computerised tomography evaluations of brain-behaviour relationships in senile dementia of the Alzheimer type. *Neurobiology of Ageing,* 1:69-79.
218	1980	Mersky, H., *et al.,* (1980) Relationships between psychological measurements and cerebral organic changes in Alzheimer's disease. *Canadian Journal of Neurological Sciences*, 7:45-49.

219	1980	Jacoby, R.J. and Levy, R. (1980) Computed tomography and the elderly: II. Senile dementia: diagnosis and functional impairment. *British Journal of Psychiatry*, 136: 256-269.
220	1980	Butler, R.N. (1980) Senility reconsidered. *Journal of the American Medical Association,* 224(3):259-263.
221	1981	Cook, R.H. and Schneck, S.A. (1981) Twins with Alzheimer's Disease. *Archives of Neurology*, 38:300-301.
222	1981	Reisberg, B. (1981) *Brain failure: An introduction to current concepts of senility*. New York: Free Press.
223	1982	Barfus, R.T., *et al.,* (1982) The cholinergic hypostudy of geriatric memory dysfunction. *Science,* 217:408-417.
224	1982	Coyle, J.T., Price, D.L. and Delong, M.R. (1982) Alzheimer's disease: a disorder of cortical cholinergic innervation. *Science,* 219:1184-1190.
225	1982	Hughes, C.P., *et al.,* (1982) A new clinical scale for the stageing of dementia. *British Journal of Psychiatry,* 140:566-572.
226	1982	Mesulam, M.M. (1982) Slowly progressive aphasia without generalized dementia. *Ann Neurol,* 11:592-598.
227	1982	Reisberg, B., *et al.,* (1982) The Global Deterioration Scale (GDS): an instrument for the assessment of primary degenerative dementia (PDD). *American Journal of Psychiatry,* 139:1136-1139.
228	1982	Robertson, D., Rockwood, K. and Stolee, P. (1982) A short mental status questionnaire. *Canadian Journal on Ageing,* 1:16-20.
229	1983	Adams, R.D. and Victor, M. (1983) Derangements of intellect, mood and behaviour. In: Petersdorf, R.G., *et al.,* (eds.) *Harrison's Principles of Internal Medicine.* New York: McGraw-Hill.
230	1983	Drachman, D.A. (1983) How Normal Ageing Relates to dementia: a critique and classification. In: Samuel, D. *et al.,* (eds.) *Ageing of the Brain.* New York: Raven Press.
231	1983	Halpert, B.P. (1983) Development of the term 'senility' as a medical diagnosis. *Minnesota Medicine,* 66(7):451-424.
232	1983	Katzman, R., *et al.,* (1983) Validation of a short orientation-memory-concentration test of cognitive impairment. *American Journal of Psychiatry,* 140:734-739.
233	1984	Clark, M., et al., (1984) A slow death of the mind. *Newsweek,* 3:25-28.

234	1984	Glenner, G. and Wong, C.W. (1984) Alzheimer's disease and Down's syndrome: Sharing of a unique cerebrovascular Amyloid fibril protein. *Biochemical and Biophysical Research Communications,* 122(3):1131-1135.
235	1984	Glenner, G. and Wong, C.W. (1984) Alzheimer's disease: initial report of the purification and characterization of a novel cerebrovascular amyloid protein. *Biochemical and Biophysical Reserach Communications,* 120(3):885-890.
236	1984	Kokmen, E. (1984) Dementia-Alzheimer Type. *Mayo Clinic Proceedings,* 59(1):35-42.
237	1984	Koss, E., *et al.,* (1984) The stroop colour-word test: indicator of dementia severity. *International Journal of Neuroscience,* 24:53-61.
238	1984	McKhann, G., *et al.,* (1984) Clinical diagnosis of Alzheimer's disease. Report of the NINCDS-ADRDA Work Group under the auspices of the Department of Health and Human Services task force on Alzheimer's disease. *Neurology,* 34:939-944.
239	1984	Rosen, W.G., Mohs, R.C. and Davis, K.L. (1984) A new rating scale for Alzheimer's disease. *American Journal of Psychiatry,* 141:1356-64.
240	1985	Berg, L. (1985) Does Alzheimer's disease represent an exaggeration of normal ageing? *Arch Neurol,* 42:1097-1105.
241	1985	Creasey, H. and Rapport, S.I. (1985) The Ageing Human Brain. *Ann. Neurol,* 17:2-10.
242	1985	Khachaturian, Z.S. (1985) Diagnosis of Alzheimer's disease. *Arch. Neurol*, 42(11):1097-1105.
243	1985	Masters, C.L., et al., (1985) Amyloid plaque core protein in Alzheimer disease and Down syndrome. *Proc Natl Acad Sci USA*, 82:4245-4249.
244	1986	Cutler, N. (1986) Public response: the national politics of Alzheimer's disease. In: Gilhooly, M., Zarit, S. and Birren, J.E. (eds.) *The Dementias: Policy and Management.* Englewood Cliffs NJ: Prentice Hall.
245	1986	Katzman, R. (1986) Alzheimer's Disease. *NEJM*, 314:964-973.
246	1986	Shulman, K., Shedletsky, R. and Silver, I. (1986) The challenge of time. Clock drawing and cognitive function in the elderly. *International Journal of Geriatric Psychiatry,* 1:135-140.

247	1986	Gubrium, J.F. (1986) *Old Timers and Alzheimer's: the Descriptive organisation of senility.* Grenwich: JAI Press.
248	1986	Volicer, L. (1986) Need for hospice approach to treatment of patients with advanced progressive dementia. *Journal of the American Geriatrics Society*, 34:655-658.
249	1986	Volicer, L., *et al.,* (1986) Hospice approach to the treatment of patients with advanced dementia of the Alzheimer type. *Journal of the Medical Association,* 256:2210-2213.
250	1987	Alzheimer's Disease and related Disorders Association, ADRDA (1987) *National Program to Conquer Alzheimer's Disease.* Chicago IL: ADRDA.
251	1987	American Psychiatric Association (1987) *Diagnostic and Statistical Manual of Mental Disorders III-R.* 3rd ed. - Revised. Washington DC: APA.
252	1987	Gibb, W.R.G., Esiri, M.M. and Lees, A.J. (1987) Clinical and pathological features of diffuse cortical Lewy body disease (Lewy body dementia). *Brain,* 110:1131-1153.
253	1987	Katzman, R. (1987) Alzheimer's Disease: advances and opportunities. *J Am Geriatr Soc,* 35:69-73.
254	1987	Teng, E.L. and Chui, H.C. (1987) The modified mini mental state (3MS) examination. *Journal of Clinical Psychiatry,* 48:314-318.
255	1987	Brun, A. (1987) Frontal lobe degeneration of the non-Alzheimer type. I. Neuropathology. *Archives of Gerontology and Geriatrics*, 6:193-208
256	1987	Gustafson, L. (1987) Frontal lobe degeneration of the non-Alzheimer type. II. Clinical picture and differential diagnosis. *Archives of Gerontology and Geriatrics,* 6:209-223.
257	1987	Hall, G.R. and Buckwalter, K.C. (1987) Progressively lowered stress: A conceptual model for care of adults with Alzheimer's disease. *Archives of psychiatric Nursing*, 1(6):399-406.
258	1987	Temg, E.I. and Chui, H.C. (1987) The Modified Mini Mental State (3MS) Examination. *Journal of Clinical Psychiatry,* 48:314-318.
259	1988	Alexopoulos, G.S., *et al.,* (1988) Cornell scale for depression in dementia. *Biological Psychiatry*, 23(3):271-284.

260	1988	Brandt, J., Spencer, M. and Folstein, M. (1988) The telephone interview for cognitive status. *Neuropsychiatry, Neuropsychology and Behavioural Neurology,* 1:111-117.
261	1988	Neary, D., *et al.,* (1988) Dementia of frontal lobe type. *Journal of Neurol Neurosurg Psychiatry*. 51:53-361.
262	1988	Benson, D., *et al.,* (1988) Posterior cortical atrophy. *Archives of Neurology,* 45(7): 789-793.
263	1988	Frogatt, A. (1988) Self-awareness in early dementia. In: Gearing, B., Johnson, M. and Heller, T. (eds.) *Mental health problems in old age: a reader.* John Wiley and Sons: Chichester, pp. 131-138.
264	1988	Reisberg, B. (1988) Functional assessment stageing (FAST). *Psychopharmacology Bulletin*, 24:653-659.
265	1988	Sunderland, T., *et al.,* (1989) Clock drawing in Alzheimer's disease. *Journal of the American Geriatrics Society,* 37:725-729.
266	1989	Davis, R. (1989) *My Journey into Alzheimer's Disease.* Wheaton Ill: Tyndale House.
267	1989	Erzigkeit, H. (1989) The SKT: a short cognitive performance test as an instrument for the assessment of clinical efficacy of cognition enhancers. In: Bergener, M. and Reisberg, B. (eds.), *Diagnosis and treatment of senile dementia.* Berlin: Springer-Verlag, pp.164-174.
268	1989	Goate, A.M. *et al.,* (1989) Predisposing locus for Alzheimer's disease on chromosome 21. *Lancet,* 1:352-355.
269	1989	Kitwood, T. (1989) "Brain, Mind and Dementia: With Particular Reference to Alzheimer's Disease." *Ageing and Society*, 9:1-15.
270	1989	Sunderland, T., *et al.,* (1989) Clock drawing in Alzheimer's disease. *Journal of the American Geriatrics Society***,** 37:725-729.
271	1989	Dick, J.P.R., *et al.,* (1989). Slowly progressive praxia. *Behav Neurol,* 2:101-114.
272	1989	White Williams, B., *et al.,* (1989) Boston naming test in Alzheimer's disease. *Neuropsychologia,* 27:1073-1079.
273	1989	Wolf-Klein, G.P., *et al.,* (1989) Screening for Alzheimer's disease by clock drawing. *Journal of the American Geriatrics Society,* 37:730-734.
274	1990	Kitwood, T. (1990) "The Dialectics of Dementia: With Particular Reference to Alzheimer's Disease." *Ageing and Society,* 10:177-196.

275	1990	Saxton, J., *et al.,* (1990) Assessment of severely impaired patients: description and validation of a new neuropsychological test battery. *Psychological Assessment,* 2:298-303.
276	1991	Chartier Harlin, M.C. *et al.,* (1991) Early onset Alzheimer's disease caused by mutations at codon 717 of the Beta-amyloid precursor protean gene. *Nature,* 353:844-846.
277	1991	Connelly, P.J. and Jamieson, F.E. (1991) Objective assessment of praxis – the OPA diagram – simply testing for dementia. *International Journal of Geriatric Psychiatry,* 6:667-672.
278	1991	Hardy, J. and Allsop, D. (1991) Amyloid deposition as the central event in the aetiology of Alzheimer's Disease. *Trends in Pharmacological Sciences,* 12:383-388.
279	1991	Molloy, D.W., Alemayehu, E. and Roberts, R. (1991) Reliability of a standardized mini-mental state examination compared with the traditional mini-mental state examination. *American Journal of Psychiatry,* 148: 102-105.
280	1991	Murrel, J. *et al.,* (1991) A mutation in the Amyloid precursor protein associated with hereditary Alzheimer's disease. *Science,* 254:97-99.
281	1991	Pericak-Vance, M.A. *et al.,* (1991) Linkage studies in familial Alzheimer's disease: Evidence for chromosome 19 linkage. *American Journal Human Genetics*, 48:1034-1050.
282	1991	Simpson, P.M., *et al.,* (1991) The cognitive drug research computerized assessment system for demented patients: a validation study. *International Journal of Geriatric Psychiatry,* 6: 95-102.
283	1992	Albert, M. and Cohen, C. (1992) The Test for Severe Impairment: an instrument for the assessment of patients with severe cognitive dysfunction. *Journal of the American Geriatrics Society,* 40:449-453.
284	1992	Eisdorfer, C., *et al.,* (1992) An empirical evaluation of the global deterioration scale for stageing Alzheimer's disease. *American Journal of Psychiatry,* 149:190-194.
285	1992	World Health Organisation (1992) *The ICD-10 Classification of Mental and Behavioural Disorders. Clinical Descriptions and Diagnostic Guidelines.* Geneva: WHO.

286	1992	Hardy, J.A. and Higgins, G.A. (1992) Alzheimer's disease: the amyloid cascade hypostudy. *Science,* 256(5054):184-185.
287	1992	Hodges, J.R., *et al.,* (1992) Semantic dementia – progressive fluent aphasia with temporal lobe atrophy. *Brain,* 115:1783-1806.
288	1992	Hurley, A.C., *et al.,* (1992) assessment of discomfort in advanced Alzheimer's patients. *Research in Nursing and Health,* 15:309-317.
289	1992	Kitwood, T. and Bredin, K. (1992) Towards a theory of dementia care: personhood and wellbeing. *Ageing and Society,* 12:269-87.
290	1993	Mendez, M.F., *et al.,* (1993) Pick's disease versus Alzheimer's disease: a comparison of clinical characteristics. *Neurology,* 43:289-292.
291	1993	Ritchie, K., *et al.,* (1993) Computerized cognitive examination of the elderly (ECO). The development of a neuropsychological examination for clinical and population use. *International Journal of Geriatric Psychiatry,* 8:899-914.
292	1994	American Psychiatric Association (1994) *Diagnostic and statistical manual of mental disorder (DSM-IV).* 4th ed. Washington DC: APA.
293	1994	Cummings, J.L., *et al.,* (1994) The neuropsychiatric inventory: comprehensive assessment of psychopathology in dementia. *Neurology,* 44:2308-2314.
294	1994	Imai, Y. and Hasegawa, K. (1994) The revised Hasegawa's dementia scale (HDS-R) - evaluation of its usefulness as a screening test for dementia. *Journal of Hong Kong College of Psychiatry,* 4:20-24.
295	1994	Manos, P.J. and Wu, R. (1994) The ten point clock test: a quick screen and grading method for cognitive impairment in medical and surgical patients. *International Journal of Psychiatry in Medicine,* 24:229-244.
296	1994	Roth, M. (1994) Dementia and Normal Ageing of the brain. In, Huppert, F.A., Brayne, C. and O'Connor, D. (eds.) *Dementia and Normal Ageing*. Cambridge University Press: Cambridge, Chapter 4, pp57-76.
297	1994	Teng, E.L., *et al.,* (1994) The Cognitive Abilities Screening Instrument (CASI): a practical test for cross-cultural epidemiological studies of dementia. *International Psychogeriatrics,* 6:45-58.
298	1994	Volicer, L., *et al.,* (1994) Measurement of severity in advanced Alzheimer's disease. *Journal of Gerontology,* 49:223-226.

299	1994	World Health Organisation (1994) *Lexicon of Psychiatric and Mental Health Terms.* Geneva: WHO.
300	1995	Levy-Lahad, E. *et al.,* (1995) Candidate gene for the chromosome 1 familial Alzheimer's disease locus. *Science,* 269:973-977.
301	1995	Shua-Haim, J.R. and Gross, J.S. (1995) Alzheimer's Syndrome and not Alzheimer's Disease. *Journal American Geriatrics Society,* 44(1):96-97.
302	1995	Evans, J.J., *et al.,* (1995) Progressive prosopagnosia associated with selective right temporal lobe atrophy – a new syndrome? *Brain,* 118:1-13.
303	1996	Brayne, C., *et al.,* (1996) Apolipoprotein E genotype in the prediction of cognitive decline and dementia in a prospectively studies elderly population. *Dementia,* 7:169-174.
304	1996	Dooneief, G., *et al.,* (1996) The clinical dementia rating scale: community-based validation of "profound" and "terminal" stages. *Neurology,* 46:1746-1749.
305	1996	Goldsmith, M. (1996) *Hearing the voice of the person with dementia.* London: Jessica Kingsley.
306	1996	Hyman, B. (1996) Alzheimer's disease or Alzheimer's diseases? Clues from molecular epidemiology. *Ann Neurol,* 40:135-136.
307	1996	Pollen, D. (1996) *Hannah's Heirs: The Quest for the Genetic Origins of Alzheimer Disease.* New York: Oxford University Press.
308	1996	Wallin, A. and Blennow, K. (1996) Clinical subgroups of Alzheimer syndrome. *Acta Neurol Scand,* 165:51-57.
309	1997	Bellelli, G., *et al.,* (1997) The Bedford Alzheimer Nursing Severity Scale for the severely demented. Validation study. *Alzheimer Disease and Associated Disorders,* 11(2):71-77.
310	1997	Brodaty, H. and Moore, C.M. (1997) The clock drawing test for dementia of the Alzheimer's type: a comparison of three scoring methods in a memory disorder clinic. *International Journal of Geriatric Psychiatry,* 12:619-62.
311	1997	Go, R.C.P., *et al.,* (1997) Development and validation of a structured telephone interview for dementia (STIDA): the NIMH genetics initiative. *Journal of Geriatric Psychiatry and Neurology,* 10:161-167.

312	1997	Kitwood, T. (1997) *Dementia reconsidered.* Buckingham: Open University Press.
313	1997	Litvan, I., *et al.,* (1997) Which clinical features differentiate progressive supranuclear palsy (Steele-Richardson-Olszewski syndrome) from related disorders? A clinicopathological study. *Brain,* 120:65-74.
314	1997	Luchins, D.J., Hanrahan, P. and Murphy, K. (1997) Criteria for enrolling dementia patients in hospice. *Journal of the American Geriatrics Society,* 45(9):1054-1059.
315	1997	Snowdon, D. (1997) Ageing and Alzheimer Disease: Lessons from the Nun Study. *The Gerontologist*, 35:150-156.
316	1997	Volicer, L., *et al.,* (1997) Persistent vegetative state in Alzheimer disease – Does it exist? *Archives of Neurology,* 54(11):1382-1384.
317	1997	World Health Organisation (1997) *Multiaxial classification of the ICD-10 for use in adult psychiatry.* Geneva: WHO.
318	1998	Inouye, S.K., *et al.,* (1998) The time and change test: a simple screening test for dementia. *Journal of Gerentology,* 54A: M281-M286.
319	1998	Solomon, P.R., *et al.,* (1998) A 7 minute neurocognitive screening battery highly sensitive to Alzheimer's disease. *Archives of Neurology,* 55:349-355.
320	1998	Tobin, S.L., *et al.,* (1998) The genetics of Alzheimer disease and the application of molecular tests. *Genetic Testing*, 3:37-45.
321	1999	Buschke, H., *et al.,* (1999) Screening for dementia with the memory impairment screen. *Neurology,* 52:231-238.
322	1999	Fogarty, M. (1999) Genetic testing. Alzheimer disease and long-term care insurance. *Genetic Testing,* 3:133-137.
323	1999	Kovach, C.R., *et al.,* (1999) Assessment and treatment of discomfort for people with late-stage dementia. *Journal of Pain and Symptom Management,* 18(6):412-419.
324	2000	American Psychiatric Association (2000) *Diagnostic and statistical manual of mental disorders, text revision.* 4th ed. Washington DC: APA.
325	2000	Audit Commission (2000) *Forget Me Not*. London: TSO.
326	2000	Belle, S.H., *et al.,* (2000) A brief cognitive screening battery for dementia in the community. *Neuroepidemiology,* 19:43-50.

327	2000	Brodaty, H., *et al.,* (2000) The GPCOG: A new screening test for dementia designed for general practice. *Journal of the American Geriatrics Society,* 50:530-534.
328	2000	Crystal, H.A., *et al.,* (2000) The relative frequency of dementia of unknown etiology increases with age and is nearly 50% in nonagenarians. *Archives of Neurology,* 57(5):713-719.
329	2000	Jacqmin-Gadda, H., *et al.,* (2000) A cognitive screening battery for dementia in the elderly. *Journal of Clinical Epidemiology,* 53:980-987.
330	2000	Tanzi, R.E. and Parson, A.B. (2000) *Decoding darkness: the search for the genetic causes of Alzheimer's disease.* New York: Basic Books.
331	2000	Harrell, L.E., *et al.,* (2000) The Severe Mini-Mental State Examination: a new neuropsychological instrument for the bedside assessment of severely impaired patients with Alzheimer's disease. *Alzheimer Disease and Associated Disorders,* 14:168-175.
332	2000	Kurz, A.F. (2000) The concept of dementia: retain, reframe, rename or replace? *International Psychogeriatrics*, 22(1):37-42.
333	2000	Mundt, J.C., Freed, D.M. and Griest, J.H. (2000) Lay person-based screening for early detection of Alzheimer's disease; development and validation of an instrument. *Journal of Gerentology,* 55B:163-170.
334	2000	Weiner, M.F., *et al.,* (2000) The quality of life in late-stage dementia (QUALID). *Journal of the American Medical Directors Association,* May/June (1):114-116.
335	2000	Sachdev, P. (2000) Is it time to retire the word "dementia"? *Journal of Neuropsychiatry and Clinical Neurosciences,* 12(2):276-279
336	2001	Appollonio, I., *et al.,* (2001) Cognitive assessment of severe dementia: the test for severe impairment (TSI). *Archives of Gerontology and Geriatrics.* 33 (Suppl. 1):25-31.
337	2001	Department for Health (2001) *National Service Framework for Older People.* London: TSO.
338	2001	O'Donnell, W.E. (2001) The neuropsychological impairment scale – senior procedure for evaluating awareness disturbance in geriatric patients. *Journal of Clinical Psychology,* 57:423-427
339	2001	Proctor, G. (2001) Listening to older women with dementia. *Disability and Society,* 16(3):361-376.

340	2001	Reisberg, B. *et al.,* (2001) The Alzheimer's disease activities of daily living international scale (ADL-IS). *International Psychogeriatrics,* 13:163-81.
341	2001	Scanlan, J. and Borson, S. (2001) The mini-cog: receiver operating characteristic with expert and naïve raters. *International Journal of Geriatric Psychiatry,* 16: 216-222.
342	2001	Volicer, L., Hurley, A.C. and Blasi, Z.V. (2001) Scales for evaluation of end-of-life care in dementia. *Alzheimer's Disease and Associated Disorders,* 15:194-200.
343	2001	World Health Organisation (2001) *International Classification of Functioning, Disability and Health*. Geneva: WHO.
344	2002	Barberger-Gateau, P., *et al.,* (2002) The Disablement process: a conceptual framework for dementia-associated disability. *Dementia and Geriatric Cognitive Disorders*, 13:60-66.
345	2002	Benedict, R.H., *et al.,* (2002) Frontal cortex atrophy predicts cognitive impairment in multiple sclerosis. *Journal of Neuropsychiatry and Clinical Neuroscience,* 14(1):44-51.
346	2002	Burns, A.S., Purandare, N. and Craig, S. (2002) *Mental Health in Older People on Practice.* London: Royal Society of Medicine Press Ltd.
347	2002	Ready, R.E., *et al.,* (2002) The Cornell-Brown Scale for Quality of Life in Dementia. *Alzheimer Diseases and Associated Disorders,* 16(2):109-115.
348	2003	Blackman, T.I.M, *et al.,* (2003) The accessibility of public spaces for people with dementia: a new priority for the open city. *Disability and Society*, 18(3):357-371.
349	2003	Brotchie, J. (2003) *Caring for someone with dementia.* Age Concern England: London.
350	2003	Clark, C.M. and Karlawish, J.H.T. (2003) Alzheimer disease: concepts and emerging diagnostic and therapeutic strategies. *Annals of Internal Medicine,* 138(5):400-411.
351	2003	Clark, C.M., *et al.,* (2003) Cerebrospinal fluid tau and beta-amyloid: how well do these biomarkers reflect autopsy-confirmed dementia diagnoses? *Archives of Neurology,* 60:1696-1702.

352	2003	Knopman, D.S., *et al.,* (2003) Neuropathology of cognitively normal elderly. *Journal Neuropathology and Experimental Neurology*, 62:1087-1095.
353	2003	Spatt, J. (2003) Arnold Pick's concept of dementia. *Cortex: A Journal Devoted to the Study of the Nervous System and Behaviour,* 39(3):525-531.
354	2003	Strozyk, D., *et al.,* (2003) CSF Aβ 42 levels correlate with amyloid-neuropathology in a population-based autopsy study. *Neurology*, 60:652-656.
355	2003	Villanueva, M.R., *et al.,* (2003) Pain assessment for the dementing elderly (PADE): Reliability and validity of a new measure. *Journal of the American Medical Directors Association,* 4(1):1-8.
356	2003	Warden, V., Hurley, A.C. and Volicer, L. (2003) Development and psychometric evaluation of the pain assessment in advanced dementia (PAINAD) scale. *Journal of the American Medical Directors Association,* 4: 9-15.
357	2003	World Health Organisation (2003) *International Classification of Primary Care (ICP-2).* 2nd ed. Geneva: WHO.
358	2004	Abbey, J., *et al.,* (2004) The Abbey pain scale: A 1-minute numerical indicator for people with end-stage dementia. *International Journal of palliative Nursing,* 10(1):6-13.
359	2004	Ballard, C.G. (2004) Definition and diagnosis of dementia with Lewy bodies. *Dementia and Geriatric Cognitive Disorders*, 17(suppl 1):15-24.
360	2004	Belgrave, L.L. (2004) Living with dementia: lay definitions of Alzheimer's disease among African American caregivers and sufferers. *Symbolic Interaction,* 27(2):199-222.
361	2004	Cummings, J.L. (2004) Alzheimer's disease. *New England Journal of Medicine,* 351:56-67.
362	2004	Davies, D.H.J. (2004) Dementia: sociological and philosophical constructions. *Social Sciences and Medicine*, 58:369-378.
363	2004	Davies, E. and Higginson, I.J. (2004) *Better Palliative Care for Older People.* Denmark: WHO.

364	2004	Fernando, M.S. and Ince, P.G. (2004) Vascular pathologies and cognition in a population based cohort of elderly people. *Journal of Neurological Sciences*, 299:136-138.
365	2004	Nolan, M., *et al.,* (2004) Beyond 'person centred' care: a new vision for gerontological nursing. *Journal of Clinical Nursing*, 13(s.1):45-53.
366	2004	Hall, S., *et al.,* (2004) *Palliative Care for Older People: Better Practices*. Denmark: WHO.
367	2005	Adams, T. and Gardiner, P. (2005) Communication and interaction within dementia care triads: developing a theory for relationship-centred care. *Dementia: International Journal for Social Research and Practice,* 4(2):185-205.
368	2005	Alzheimer's Society (2005) *Policy position: demography.* London: Alzheimer's Society.
369	2005	Ball, M.J. (2005) Commentary on "Diagnosis of Alzheimer's disease: Two decades of progress." Evolving neuropathological definitions of Alzheimer's disease: Where we came from and where we might go. *Alzheimer's and Dementia,* 1(2):114-115.
370	2005	Beattie, A., *et al.,* (2005) They don't quite fit the way we organise our services – results from a UK field study of marginalised groups and dementia care. *Disability and Society*, 20(1):67-80.
371	2005	Bryden, C. (2005) *Dancing with dementia.* London: Jessica Kingsley.
372	2005	Buracchio, T., Arvanitakis, Z. and Gorbien, M. (2005) Dementia with Lewy bodies: current concepts. *Dementia and Geriatric Cognitive Disorders*, 20(5):306-320.
373	2005	Care Services Improvement Partnership (CSIP) (2005) *Everybody's Business – Integrated mental health services for older adults: a service development guide.* London: DH.
374	2005	Dorenlot, P. (2005) Editorial. *Dementia,* 4(4):459-461.
375	2005	Gilliard, J., *et al.,* (2005) Dementia care in England and the social model of disability. *Dementia: international Journal for Social Research and Practice,* 4(4):571-586.
376	2005	Hampel, H., *et al.,* (2005) Correlation of cerebrospinal fluid levels of tau protein phosphorylated at threonine 231 with rates of hippocampal atrophy in Alzheimer's disease. *Archives of Neurology,* 62:770-773.

377	2005	Hoe J, *et al.,* (2005) Use of the Qol-AD for measuring quality of life in people with severe dementia – the LASER-AD study. *Age and Ageing*, 34(2):130-135.
378	2005	Tanzi, R.E. and Bertram, L. (2005) Twenty years of the Alzheimer's disease Amyloid hypostudy: A genetic perspective. *Cell*, 4: 545-555.
379	2005	Nasreddine, Z.S. *et al.,* (2005) The Montreal Cognitive Assessment (MoCA): a brief screening tool for mild cognitive impairment. *Journal of American Geriatric Society,* 53(4):695-699.
380	2006	Apostolova, L.G., *et al.,* (2006) Conversion of mild cognitive impairment to Alzheimer disease predicted by hippocampal atrophy maps. *Archives of Neurology*, 63:693-699.
381	2006	Bennett, D.A., *et al.,* (2006) Neuropathology of older persons without cognitive impairment from two community-based studies. *Neurology*, 66:1837-1844.
382	2006	Breitner, J.C.S. (2006) Dementia – epidemiological considerations, nomenclature, and a tacit consensus definition. *Journal of Geriatric Psychiatry and Neurology*, 19(3):129-136.
383	2006	Buerger, K., *et al.,* (2006) CSF phosphorylated tau protein correlates with neocortical neurofibrillary pathology in Alzheimer's disease. *Brain,* 129:3035-3041.
384	2006	Jagust, W. (2006) Positron emission tomography and magnetic resonance imageing in the diagnosis and prediction of dementia. *Alzheimer's and Dementia,* 2(1):36-42.
385	2006	NICE/SCIE (2006) *Dementia: Supporting people with dementia and their carers in health and social care.* London: TSO.
386	2006	Mioshi, *et al.,* (2006) The addenbrooke's cognitive examination revised (ACE-R): a brief cognitive test battery for dementia. *International Journal of the Geriatric Society,* 21(11):1078-1085.
387	2006	Reisberg, B. (2006) Diagnostic criteria in dementia: a comparison of current criteria, research challenges, and implications for DSM-V. *Journal of Geriatric Psychiatry and Neurology,* 19(3):137-146.
389	2007	Bartlett, R. and O'Connor, D. (2007) From personhood to citizenship: broadening the lens for dementia practice and research. *Journal of Ageing Studies,* 21:107-118.

390	2007	Brooker, D. (2007) *Person Centred Care.* London: Jessica Kingsley.
391	2007	*Devanand, D.P., et al., (2007)* Hippocampal and entorhinal atrophy in mild cognitive impairment: prediction of Alzheimer disease*. Neurology,* 68:828-836.
392	2007	Dubois, B., *et al.,* (2007) research criteria for the diagnosis of Alzheimer's disease: revising the NINCDS-ADRDA criteria. *Lancet: Neurology,* 6:734-746.
393	2007	Ettema, T.P., *et al.,* (2007) QUALIDEM: Development and evaluation of a dementia specific quality of life instrument. *International Journal of Geriatric Psychiatry,* 22(6):549-556.
394	2007	Falk, H., Oersson, L.O. and Wijk, H. (2007) A psychometric evaluation of a Swedish version of the Quality of Life in Late-stage dementia (QUALID) scale. *International Journal of Geriatric Psychiatry*, 22(6): 549-556.
395	2007	Jellinger, K.A. (2007) The enigma of vascular cognitive disorder and vascular dementia. *Acta Neuropathology,* 113:349-388.
396	2007	Knapp, M., *et al.,* (2007) *Dementia UK: the full report.* London: Alzheimer's Society.
397	2007	National Audit Office (2007) *Improving services and support for people with dementia.* London: TSO.
398	2007	Schneider, J.A., *et al.,* (2007) Mixed brain pathologies account for most dementia cases in community-dwelling older persons. *Neurology*, 69:2197-2204.
399	2007	Schuler, M.S., *et al.,* (2007) Psychometric properties of the German "Pain Assessment in Advanced Dementia Scale" (PAINAD-G) in nursing home residents. *Journal of the American Medical Association*, 8(6):388-395.
400	2007	Wolf-Klein, G., *et al.,* (2007) Conceptualizing Alzheimer's disease as a terminal medical illness. *American Journal of Hospice and Palliative Medicine,* 24(1):77-82.
401	2008	Bertram, L. and Tanzi, R.E. (2008) Thirty years of Alzheimer's disease genetics: Systematic meta-analyses herald a new era. *Nature Reviews Neuroscience,* 9:768-778.

402	2008	Butler, R. (2008) *The longevity revolution: the benefits and challenges of living a long life.* New York: Public Affairs.
403	2008	Cyck, L.M. and Wright, H.H. (2008) Frontotemporal dementia: its definition, differential diagnosis, and management. *Aphasiology,* 22(4): 422-444.
404	2008	Dello Russo, C., *et al.,* (2008) Validation of the Italian version of the discomfort scale-dementia of the Alzheimer type. *Journal of Advanced Nursing*, 64(3):298-304.
405	2008	Department of Health (2008) *End of Life Care Strategy: Promoting high quality care for all adults at the end of life*. London: DH.
406	2008	Downs, M. and Bowers, B. (2008) *Excellence in dementia care: research into practice.* Buckingham: Open University.
407	2008	Goetz, C.G., Emre, M. and Dubois, B. (2008) Parkinson's disease dementia: definitions, guidelines, and research perspectives in diagnosis. *Annals of Neurology,* 64(suppl):S81-S92.
408	2008	Hachinski, V, (2008) Shifts in thinking about dementia. *Journal of the American Medical Association*, 300: 2171-2173.
409	2008	Whitehouse, P.J. and George, D. (2008) *The myth of Alzheimer's: what you aren't being told about today's most dreaded diagnosis*. New York: St Martin's.
410	2009	Aarsland, D., *et al.,* (2009) Cognitive impairment in incident, untreated Parkinson's disease: the Norwegian ParkWest study. *Neurology*, 72(13):1121-1126.
411	2009	Alzheimer's Society (2009) *Counting the cost: caring for people with dementia on hospital wards*. London: Alzheimer's Society.
412	2009	Alzheimer's Association (2009) *Alzheimer's disease facts and figures.* Chicago: Alzheimer's Association.
413	2009	Davis, S., *et al.,* (2009) Guiding design of dementia friendly environments in residential care settings: Considering the living experiences. *Dementia,* 8(2):185-203.
414	2009	Department of Health (2009) *Living well with dementia: a national dementia strategy*. London: DH.
417	2009	Hardy, J. (2009) The amyloid hypostudy for Alzheimer's disease: a critical reappraisal. *Journal of Neurochemistry*, 110(4):1129-34.

418	2009	Holland, D., *et al.,* (2009) Subregional neuroanatomical change as a biomarker for Alzheimer's disease. *Proceedings of the Natural Acadamey of Sciences of United States of America,* 106: 20954-20959.
419	2009	Iacono, D., *et al.,* (2009) The Nun study. Clinically silent AD, neuronal hypertrophy and linguistic skills in early life. *Neurology*, 73: 665-673.
420	2009	Jellinger, K.A. (2009) Criteria for the neuropathological diagnosis of dementing disorders: routes out of the swamp? *Acta Neuropathology,* 117: 101-110.
421	2009	Minati, L., *et al.,* (2009) Current concepts in Alzheimer's disease: a multidisciplinary review. *American Journal of Alzheimer's Disease and Other Dementias,* 24(2):95-121.
422	2009	Mitchell, S.L., *et al.,* (2009) The clinical course of advanced dementia. *New England Journal of Medicine*, 361(16):1529-1538.
423	2009	Moreira, T. and Palladino, P. (2009) Ageing between gerontology and biomedicine. *BioSocieties,* 4(4):349-365.
424	2009	Shaw, L.M., *et al.,* (2009) Alzheimer's Disease Neuroimageing Initiative. Cerebrospinal fluid biomarker signature in Alzheimer's disease neuroimageing initiative subjects. *Annals of Neurology*, 65(4):403-413.
425	2009	Sampson L, *et al.,* (2009) End of life care for people with dementia. London: Marie Curie Palliative Care Research Unit, UCL.
426	2009	Sava, G.M., *et al.,* (2009) Age, Neuropathology and Dementia. *New England Journal of Medicine,* 360(22):2302-2309.
427	2009	Tapiola, T., *et al.,* (2009) Cerebrospinal fluid β-amyloid 42 and tau proteins as biomarkers of Alzheimer-type pathologic changes in the brain. *Archives of Neurology*, 66:382-389.
428	2010	Adams, T. (2010) The applicability of a recovery approach to nursing people with dementia. *International Journal of Nursing Studies*, 47:626-634.
429	2010	Biennow, K., *et al.,* (2010) Cerebrospinal fluid and plasma biomarkers in Alzheimer's disease. *Nature Reviews Neurology,* 6:131-144.
430	2010	Brittain, K. *et al.,* (2010) Ageing in place and technologies of place: the lived experience of people with dementia in changing social, physical

		and technological environments. *Sociology of Health and Illness,* 32(2):272-287.
431	2010	Carlino, E. *et al.,* (2010) Pain perception and tolerance in patients with frontotemporal dementia. *Pain*, 151(3):783-789.
432	2010	Dementia Action Alliance (2010) National dementia declaration. London: Dementia Action Alliance.
433	2010	Dubois, B. *et al.,* (2010) Revising the definition of Alzheimer's disease: a new lexicon. *Lancet: Neurology*, 9:1118-1127.
434	2010	Grinberg, L.T. and Heinsen, H. (2010) Toward a pathological definition of vascular dementia. *Journal of the Neurological Sciences*, 299:136-138.
435	2010	Jicha, G.A. and Carr, S.A. (2010) Conceptual evolution in Alzheimer's disease: implications for understanding the clinical phenotype of progressive neurodegenerative disease. *Journal of Alzheimer's Disease*, 19:253-272.
436	2010	Richards, M. and Brayne, C. (2010) What do we mean by Alzheimer's disease? *British Medical Journal,* 341:c4670.
438	2010	Jack, C.R. Jr., *et al.,* (2010) Hypothetical model of dynamic biomarkers of the Alzheimer's pathological cascade. *Lancet: Neurology,* 9(1):119-128.
439	2010	Jicha, G.A. and Carr, S.A. (2010) Conceptual evolution in Alzheimer's disease: implications for understanding the clinical phenotype of progressive neurodegenerative disease. *Journal of Alzheimer's Disease*, 19:253-272.
440	2010	Luengo-Fernandez, R., Leal, J. and Gray, A. (2010) Dementia 2010. *The economic burden of dementia and associated research funding in the United Kingdom.* London: Alzheimer's Research Trust.
441	2010	Neuropathology Group of the Medical Research Council Cognitive Function and Ageing Study (MRC CFAS) (2010) Pathological correlates of late-onset dementia in a multi-centre community-based population in England and Wales. *Lancet,* 357:169-175.
442	2010	Richards, M. and Brayne, C. (2010) What do we mean by Alzheimer's disease? *British Medical Journal,* 341:865-867.

443	2010	Teipel, S.J., *et al.,* (2010) Multicentre variability of MRI-based medial temporal lobe volumetry in Alzheimer's disease. *Psychiatry Research: Neuroimaging,* 182(3):244-250.
444	2010	The Scottish Government (2010) Scotland's National Dementia Strategy. Edinburgh: The Scottish Government.
445	2010	Thomas, C. (2010) Medical sociology and disability theory. In: Scambler, G. and Scambler, S. (eds.) *New directions in the sociology of chronic and disabling conditions: assaults on the life world*. Basingstoke: Palgrave Macmillan, pp. 37-56.
446	2011	Behuniak, S.M. (2011) The living dead? The construction of people with Alzheimer's disease as zombies. *Ageing and Society*, 31:70-92.
447	2011	George, D.R., Whitehouse, P.J. and Ballenger, J. (2011) The evolving classification of dementia: placing the DSM-V in a meaningful historical and cultural context and pondering on the future of "Alzheimer's". *Culture, Medicine and Psychiatry*, 35:417-435.
448	2011	McKhann, G.M., *et al.,* (2011) The diagnosis of dementia due to Alzheimer's disease: recommendations from the national institute on ageing – Alzheimer's association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimer's and Dementia*, 7(3):263-269.
449	2011	McKhann, G.M. (2011) Changing concepts of Alzheimer disease. *The Journal of the American Medical Association*, 305(23):2458-2459.
450	2011	Niedermeyer, E. and Ghigo, J.O. (2011) Alzheimer dementia: an overview and a promising new concept. *American Journal of Electroneurodiagnositic Technology*, 51:82-91.
451	2011	Young, J., *et al.,* (2011) National Audit of Dementia (NAD). *Report of the national audit of dementia care in general hospitals 2011.* Royal College of Psychiatrists online report www.rcpsych.ac.uk/pdf/NAD.
452	2011	Sperling, R.A., *et al.,* (2011) Towards defining the preclinical stages of Alzheimer's disease: recommendations from the National Institute on Ageing- Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimer's and Dementia,* 7(3):280-292.
453	2011	Thuathail, N. and Welford, C. (2011) Pain assessment tools for older people with cognitive impairment. *Nursing Standard*, 26(6):39-46.

454	2011	Varghese, P.B., Castellano, J.M. and Holtzmann, D.M. (2011) Roles of apolipoprotein E in Alzheimer's disease and other neurological disorders. *Lancet Neurology,* 10(3):241-252.
455	2011	Welsh Government (2011) *National dementia vision for Wales.* Cardiff: Welsh Government.
456	2011	Department of Health, Social services and public safety (DHSSPS) (2011) *Improving dementia services in northern Ireland. A regional strategy*. Belfast: DHSSPS.
457	2012	All Party Parliamentary Group on Dementia (2012) *Unlocking diagnosis*. London: Alzheimer's Society.
458	2012	Department of Health (2012) *Prime Minister's challenge on dementia: delivering major improvements in dementia care and research by 2015*. London: DH.
459	2012	Jack, C.R. Jr. (2012) Alzheimer disease: new concepts on its neurobiology and the clinical role imageing will play. *Radiology*, 263(2): 344-361.
460	2012	Jordan, A., *et al*., (2012) pain and distress in advanced dementia: choosing the right tools for the job. *Palliative Medicine*, 26(7):873-878.
461	2012	Meng, X. and D'Arcy, C. (2012) Education and dementia in the context of the cognitive reserve hypostudy: a systematic review with meta-analysis and qualitative analyses. *PLoS ONE*, 7(6):e38268.
462	2012	Mielke, M.M., Montine, T. and Khachauturian, A.S. (2012) Vascular diseases: one pathway toward new conceptual models of dementia. *Alzheimer's and Dementia,* 8(5):S69-70.
463	2012	Ramirez-Bermudez, J. (2012) Alzheimer's disease: critical notes on the history of a medical concept. *Archives of Medical Research,* 43(8):595-599.
464	2012	WHO and Alzheimer's Disease International (2012) *Dementia: a public health priority.* Geneva: WHO.
465	2013	All Party Parliamentary Group on Dementia (2013) *Dementia does not discriminate*. London: Alzheimer's Society.
466	2013	Alzheimer's Society (2013) *The hidden voice of loneliness.* London: Alzheimer's Society.

467	2013	Alzheimer's Society (2013) *Building dementia-friendly communities: a priority for everyone*. London: Alzheimer's Society.
468	2013	American Psychiatric Association (2013) *Diagnostic and statistical manual of mental disorders - DSM-5*. Washington DC: APA.
469	2013	Benhabib, H., *et al.,* (2013) Responsiveness of the QUALID to improved neuropsychiatric symptoms in patients with Alzheimer's disease. *Canadian Geriatric Journal*, 16(4):180-185.
470	2013	Carers Trust (2013) *Triangle of care – carers included: a guide to best practice for dementia care.* London: Carers Trust.
471	2013	Galindo-Garre F, *et al.,* (2013) The BANS-S to assess dementia severity in advanced dementia: a non-parametric item response analysis and a study of its validity. *American Journal of Alzheimer's Disease and other Dementias,* 29(1):84-89.
472	2013	Holmes, C. (2013) Review: A systemic inflammation and Alzheimer's disease. *Neuropathology and Applied Neurobiology*, 39(1):51-68.
473	2013	Love, K. and Pinkowitz, J. (2013) Person-centred care for people with dementia: a theoretical and conceptual framework. *Journal of the American Society on Ageing*, 37(3):23-29.
474	2013	Pinzon, L.C., *et al.,* (2013) Dying with dementia: symptom burden, quality of care, and place of death. *Deutsches Arzteblatt International*, 110(12):195-202.
475	2013	Simard, J. (2013) *The End-of-Life Namaste Care Program for People with dementia.* (2nd ed.). Baltimore Health Professional Press.
476	2013	Warren, J.D., Rohrer, J.D. and Rossor, M.N. (2013) Clinical review: frontotemporal dementia. *British Medical Journal*, 347:f4827.
477	2013	Williams, M.M., *et al.,* (2013) Progression of Alzheimer's disease as measured by Clinical Dementia Rating Sum of Boxes scores. *Alzheimer's and Dementia*, 9 (Suppl 1):S39-S44.
478	2014	Abudy, A., Juven-Wetzler, A. and Zohar, J. (2014) The different faces of Creutzfeldt-Jacob disease CJD in psychiatry. *General Hospital Psychiatry*, 36(3):245-248.
479	2014	Alzheimer's Society (2014) *Dementia UK. 2nd ed*. London: Alzheimer's Society.

480	2014	Alzheimer's Society (2014) *How to help people with dementia: a guide for customer-facing staff*. London: Alzheimer's Society.
481	2014	All-Party Parliamentary Group on Dementia (2014) *Building on the national dementia strategy: change, progress and priorities.* London: Alzheimer's Society.
482	2014	Alzheimer's Society (2014) *Dementia 2014: Opportunity for Change.* London: Alzheimer's Society.
483	2014	Barnes, D.E., *et al*., (2014) Traumatic brain injury and risk of dementia in older veterans. *Neurology*, 83(4):312-319.
484	2014	Boyle, G. (2014) Recognising the agency of people with dementia. Disability and Society, 29(7):1130-1144.
485	2014	Centre for Economics and Business Research (2014) *Cost of dementia to business*. London: Centre for Economics and Business Research.
486	2014	Employers for Carers (2014) *Supporting employees who are caring for someone with dementia.* London: Carers UK.
487	2014	Godbolt, A.K., Cancelliere, C. and Hincapié, C.A. (2014) Systematic review of the risk of dementia and chronic cognitive impairment after mild traumatic brain injury: results of the International Collaboration on Mild Traumatic Brain Injury Prognosis. *Archives of Physical Medicine and Rehabilitation,* 95(3):Suppl.S245-S256.
488	2014	Grijalvo-Perez, A.M. and Litvan, I. (2014) Corticobasal degeneration. *Seminars in Neurology*, 34(2):160-173.
489	2014	Hendriks, S.A. *et al.,* (2014) Dying with dementia: symptoms, treatment and quality of life in the last week of life. *Journal of Pain Symptom Management*, 47(4):710-720.
490	2014	Karch, C.M. *et al.,* (2014) Alzheimer's disease genetics: from the bench to the clinic. *Neuron,* 83(1):11-26.
491	2014	Prince, M. *et al.,* (2014) *Dementia UK: Second edition – Overview.* London: Alzheimer's Society.
492	2014	Sacktor, N. and Robertson, K. (2014) Evolving clinical phenotypes in HIV-associated neurocognitive disorders. *Current Opinion in HIV and AIDS,* 9(6):517-520.
493	2014	Schroeter, M.L. *et al.,* (2014) Conceptualizing neuropsychiatric diseases with multimodal data-driven meta-analyses – The case of

		behavioural variant frontotemporal dementia. *Cortex: A Journal Devoted to the Study of the Nervous System and Behaviour*, 57:22-37.
494	2015	Alexopoulos, P. and Kurz, A. (2015) The new conceptualization of Alzheimer's disease under the microscope of influential definitions of disease. *Psychopathology*, 48(6):359-367.
495	2015	Dening, T. and Sandilyan, M.B. (2015) Dementia: definitions and types. *Nursing Standard,* 29(37):37-42.
496	2015	Mental Health Foundation (2015) *Dementia, rights, and the social model of disability: a new direction for policy and practice?* London: Mental Health Foundation.
497	2015	Shih-Yin, L. and Lewis, F.M. (2015) Dementia friendly, dementia capable and dementia positive: concepts to prepare for the future. *Gerontologist*, 55(2):237-244.
498	2015	Thomas, C. and Milligan, C. (2015) *How can and should UK society adjust to dementia?* York: Joseph Rowntree Foundation
499	2015	Volicer, L. and Hurley, A. (2015) *Assessment Scales for Advanced dementia*. Baltimore: HPP.
500	2016	Lloret, A., Fuchsberger, T., Giraldo, E. and Vina, J. (2016) Reductive stress: a new concept in Alzheimer's disease. *Current Alzheimer Research*, 13(2):206-211.

Appendix 4: Some examples of texts excluded from the *Archive* (see Section 4.7 Reflexivity in the research process)

Note: These documents are still to be regarded as important texts but were mainly excluded due to the practical constraints of the number of documents that could be analysed in the *Archive* (max. 500), and by a neeed to avoid an anti-psychiatric bias in documkent selection as discussed in section 4.7 . There inclusion in this list is not intended to deny or de-limit their relevance.

- Adams, T. (2005) From person-centred care to relationship centred care. *Generations Review,* 15(1):4-7.
- Adelman, R.C. (1998) The Alzheimerization of aging: a brief update. *Experimental Gerontology,* 33(1/2):155-157.
- Ariga, H. (2015) Common mechanisms of onset of cancer and neurodegenerative diseases. *Biological and Pharmaceutical Bulletin*, 6: 795-808.
- Baglietto-Vargas, D., *et al.,* (2015) Short-term modern life-like stress exacerbates Abeta-pathology and synapse loss in 3xTg-AD mice. *Journal of Neurochemistry,* 134(5): 915-926.
- Barnett, E. (2000) Including the person with dementia in designing and delivering care: I need to be me! London: Jessica Kingsley.
- Bartlett, R. and O'Connor, D. (2007) From personhood to citizenship: broadening the lens for dementia practice and research. *Journal of Aging Studies*, 21(2):107-118.
- Beard, R.L. (2004) In their voices: identity preservation and experiences of Alzheimer's disease. Journal of Aging Studies, 18(4):415-428.
- Beaumont, H. (2009) Losing Clive to Younger Onset Dementia. London: Jessica Kingsley.
- Benbow, S.M. and Reynolds, D. (2000) Challenging the stigma of Alzheimer's disease. *Hospital Medicine,* 61(3):174-177.

- Brannelly, T. (2007) Citizenship and care for people with dementia: values and approaches. In: Balloch, S. and Hill, M. (eds.). Care, community and citizenship: research and practice in changing policy context. Bristol: Policy, pp.89-101.

- Bredesen, D.E. (2015) Metabolic profiling distinguishes three subtypes of Alzheimer's disease. *Aging,* 7(8):595-600.

- Calhoun, R.B. (1978) In search of the new old: Redifining old age in America, 1945-1970. New York: Elsevier.

- Camp, C.J. (1998) Memory interventions for normal and pathological older adults. In: Schulz, R., Maddox, G. and Lawton, M.P. (eds.) Ann*ual review of gerontology and geriatrics, vol. 18, interventions and research with older adults*. New York: Springer.

- Caracciolo, F. (2006) Alzheimer: A Journey Together. London: Jessica Kingsley.

- Choi, S.H., *et al.,* (2014) A three-dimensional human neural cell culture model of Alzheimer's disease. *Nature,* 515(7526): 274-278.

- Clare, L. and Woods, B. (2001) A role for cognitive rehabilitation in dementia care. *Neuropsychol Rehabilitation,* 11: 193-196.

- Clarke, C.L. (1999) Family care-giving for people with dementia: some implications for policy and proifessional practice. Journal of Advanced Nursing, 29(3):712-720.

- Clarke, C.L. (2000) Risk: constructing care and care environments in dementia. *Health, Risk and Society,* 2(1):83-93.

- Clarke, C.L. *et al.,* (2010) Dementia and risk: contested territories of evberyday life. *Journal of Nursing and Healthcare of Chronic Illness,* 2(2):102-112.

- Clarke, C.L. et al., (2011) Risk assessment and management for living well with dementia. London: Jessica Kingsley.
- Conboy, I.M., *et al.,* (2005) Rejuvenation of aged progenitor cells by exposure to a young systemic environment. *Nature,* 433(7027): 760-764.
- Corder, E., *et al.,* (1993) Gene dose of apolipoprotein E type 4 alle and the risk of Alzheimer's disease in late onset familiries. *Science,* 261: 921-923.
- Constantinidis, J., Richard, J. and Tissot, R. (1974) Pick's disease. Histological and clinical correlations, *European Neurology,* 11(4): 208-217.
- Cramer, P.E., *et al.,* (2012) ApoE-directed therapeutics rapidly clear beta-amyloid and reverse deficits in AD mouse models. *Science,* 335(6075): 1503-1506.
- De Strooper, B. and Karran, E. (2016) The cellular phase of Alzheimer's disease. Cell, 164(4): 603-615.
- Department of Health (2015) Prime Minister's challenge on dementia 2020. London: DH.
- Donaghy, I. (2014) Dear dementia: the laughter and the tears. London: Hawker Publications.
- Engstrom, E.J. (2007) Researching dementia in Imperial Germany: Alois Alzheimer and the economies of psychiatric practice. *Culture, Medicine and Psychiatry,* 31:405-413.
- Enserink, M. (1998) First Alzheimer's diagnosis confirmed. *Science,* 27:2037.
- Erikson, K.I., *et al.,* (2011) Exercise training increases size of hippocampus and improves memory. *Proceedings of the National Academy of Sciences*, 108(7): 3017-3022.

- Farina, N., Rusted, J. and Tablet, N. (2014) The effect of exercise interventions on cognitive outcome in Alzheimer's disease: a systematic review. *International Psychogeriatrics*, 26(1): 9-18.
- Fray, M.T. (2000) Caring for Kathleen. Kidderminster: BILD Publications.
- Gajdusek, D.C. (1964) Attempt to demonstrate a transmissible agent in Kuru, amyotrophic lateral sclerosis, and the sub-acute and chronic nervous system degeneration of man. *Nature*, 204(4955): 257-259.
- Games, D., et al., (1995) Alzheimer-type neuropathology in transgenic mice overexpressing $V_{717}F$ beta-amyloid precursor protein. *Nature,* 373(6514): 523-527.
- Goate, A., *et al.,* (1991) Segregation of a missense mutation in the amyloid precursor protein gene with familial Alzheimer's disease. *Nature,* 349(6311): 704-706.
- Golander, H. and Raz, A.E. (1996) The mask of dementia: images of "demented residents" in a nursing ward. *Aging and Society,* 16:269-285.
- Goldgaber, D., *et al.,* (1987) Characterization and chromosomal localization of a cDNA encoding brain amyloid of Alzheimer's disease. *Science,* 235(4791): 877-880.
- Graeber, M.B. and Mehraein, P. (1999) Reanalysis of the first case of Alzheimer's disease. European Archives of Psychiatrry and Clinical Neuroscience, 249(Suppl.3):10-13.
- Hakola, H.P. (1972) Neuropsychiatric and gentic aspects of a new hereditary disease characterising progressive dementia and lipomembranous polycystic osteodysplasia. *Acta Psychiatr Scand,* Suppl. 232: 1-173.
- Heston, L.L., *et al.,* (1981) Dementia of the Alzheimer type. Clinical genetics, natural history, and associated conditions. *Archives of General Psychiatry,* 38(10): 1085-1090.

- Hock, C., *et al.,* (2003) Antibodies against beta-amyloid slow cognitive decline in Alzheimer's disease. *Neuron,* 38(4): 547-554.
- Hofmann, M., *et al.,* (1996) Interactive computer-based cognitive training in patienst with Alzheimer's disease. *Journal of Psychiatric Research,* 30: 493-501.
- Jaunmuktane, Z. *et al.,* (2015) Evidence for human transmission of amyloid-ß pathology and cerebral amyloid angiopathy. *Nature,* 525(7568): 247-250.
- Jennings, B. (2003) Hospice and Alzheimer's disease: a study in access and simply justice. *Hastings Centre Report Special Supplement,* 33:S24-S26.
- Kang, J.E., *et al.,* (1987) The precursor of Alzheimer's disease amylid A_4 protein resembles a cell-surface receptor. *Nature,* 325(6106): 733-736.
- Kang, J.E., *et al.,* (2009) Amyloid-ß dynamics are regulated by orexin and the sleep-wake cycle. *Science,* 326 (5955): 1005-1007.
- Kaplan, J. (1953) A social programme for older people. Minneapolis, MN: University of Minnesota Press,
- Katzman, R. (1993) Education and the prevalence of dementia and Alzheimer's disease, *Neurology,* 43: 13-20.
- Kawashima, R., *et al.,* (2005) Reading aloud and arithmetic calculation improve frontal function of people with dementia. *The Journals of Gerentology,* 60(3): 380-384.
- Kesslack, J.P., Niclaul, K. and Sendman, C. (1997) Memory training for individuals with Alzheimer's disease improves name recall. *Alzheimer's Research,* 3: 151-157.
- Killick, J. (2008) You Are Words: Dementia Poems. London: Hawker Publications.

- Kitwood, T. (1987) Dementia and its pathology: in brain, mind or society? *Free Associations*, 1(8):81-93.
- Kitwood, T. (1987) Explaining senile dementia: the limits of neuropathological research. *Free Associations*, 1(10):117-140.
- Kitwood, T. (1997) The experience of dementia, Ageing and Mental Health, 1:13-22.
- Kitwood, T. (1998) The technical, the personal and the framing of dementia. Social Behaviour, 3:161-179.
- Knopman, D.S. *et al.,* (2001) Practice parameter: diagnosis of dementia (an evidence based review): report of the quality standards subcommittee of the American academy of neurology. *Neurology,* 56(9):1143-1153.
- Kosaka, *et al.,* (1976) Pre-senile dementia with Alzheimer – Pick – and Lewy-body changes. *Acta Neuropathologica,* 36(3): 221-233.
- Leibing, A. and Cohem, L. (2006) Thinking about dementia: culture, loss and the anthropology of senility. New Brunswick, NJ: Rutgers University Press.
- Lewis, A. (1946) Ageing and senility: a major problem of psychiatry. *Journal of Mental Science*, 92:150-170.
- Lømo, T. (2003) The discovery of long-term potentiation. *Philosophical Transactions of the Royal Society of London B,* 358(1432): 617-620.
- Luchins, D.J. *et al.,* (1997) Criteria for enrolling dementia patients in hospice. *American Journal of Geriatrics Soc.,* 45:1054-1059.
- Mander, B.A., *et al.,* (2015) ß-amyloid disrupts human NREM slow waves and realted hippocampus-dependent memory consolidation. *Nature Neuroscience,* 18(7): 1051-1057.

- Mapstone, M., *et al.,* (2014) Plasma phospholipids identify antecedent memory impairment in older adults. *Nature Medicine,* 20(4): 415-418.
- McArthur, J.C., *et al.,* (1993) Dementia in AIDS patients: incidence and risk factors. *Neurology,* 43(11): 2245-2252.
- McCarthy, B. (2012) Hearing the person with dementia. Person-centred approaches for families and caregivers. London: Jessica Kingsley
- McCarthy, M., *et al.,* (1997) The experience of dying with dementia: a retrospective study. *International Journal of Geriatric Psychiatry,* 12:404-409.
- McCay, C., *et al.,* (1957) Parabiosis between old and young rats. *Gerentologia*, 1(1): 7-17.
- McGeer, P.L., *et al.,* (1987) Reactive microglia in patients with senile dementia of the Alzheimer type are positive for the histocompatibility glycoprotein HLA-DR. *Neuroscience Letters*, 79(1-2): 195-200.
- McGowin, D.F. (1993) Living in the Labyrinth: A Personal Journey through the Maze of Alzheimer's. Cambridge: Mainsail Press.
- Mitchell, S.L. *et al.,* Dying with advanced dementia in the nursing home, *Archives of Intern. Medicine,* 164:321-326.
- Mitchell, S.L., *et al.,* (2009) The clinical course of advanced dementia. *New England Journal of Medicine,* 361:1529-1538.
- Mittler, P. (2011) Editorial: Journey into Alzheimerland. *Dementia,* 10(2):145-147.
- Moore, S., *et al.,* (2001) Memory training improves cognitive ability in patients with dementia. *Neuropsycho Rehabilitaion,* 11: 245-261.
- Moran, M., *et al.,* (2005) Sleep disturbance in mild to moderate Alzheimer's disease. *Sleep Medicine,* 6(4): 347-352.

- Morris, M.C., *et al.,* (2105) MIND diet associated with reduced incidence of Alzheimer's disease. *Alzheimers and Dementia*, 11(9): 1007-1014.
- Mortimer, J.A., Schuman, L. and French, L. (1981) Epidemiology of dementing illness. In: Mortimer, J.A. and Schuman, L.M. (eds.) The epidemiology of dementia: monographs in epidemiology and biostatistics. New York: Oxford University Press, pp. 323-333.
- Mullard, A. (2016) Alzheimer amyloid hypothesis lives on. *Nat Rev Drug Discov.,* 16(1):3-5.
- Nascher, I.J. (1911) Senile mentality. *International Clinics*, 4:48-59.
- Nedergaard, M. (2013) Garbage truck of the brain. *Science,* 340(6140): 1529-1530.
- Nelson, L. and Tablet, N. (2015) Slowing progression of Alzheimer's disease: what works? *Ageing Research Reviews,* 23, Pt B: 193-209.
- Newton, R.D. (1948) The identity of Alzheimer's disease and senile dementia and their relationship to senility. *British Journal of Psychiatry,* 94(395): 225-249.
- Osler, W. (1905) Valedictory address at John Hopkins University. *Journal of the Medical Association*, 44: 705-710.
- Portacolone, E., Berridge, C., Johnson, J. and Schicktanz, S. (2014) Time to reinvent the science of dementia: the need for care and social integration. *Aging and Mental Health,* 18(3):269-275.
- Post, S. (1995) The moral challenge of Alzheimer disease. Baltimore, Maryland: Johns Hopkins University Press.
- Post, S. (2000) The moral challenge of Alzheimers disease. (2nd ed.) Baltimore, Maryland: Johns Hopkins University Press.

- Post, S.G. and Whitehouse, P.J. (1998) Genetic testing for Alzheimer's disease: ethical and clinical issues. Baltimore: Johns Hopkins University Press.
- Pulsford, D. and Thompson, R. (2013) Dementia – support for family and friends. London: Jessica Kingsley.
- Reed, J., et al., (2002) Services for younger people with dementia: problems with differentiating needs on the basis of age. Dementia, 1(1):95-112.
- Robakis, N.K., *et al.,* (1987) Molecular cloning and characterisation of a cDNA encoding the cerebrovascular and the neuritic plaque amyloid peptides. *Proceedings of the National Academy of Sciences of the United States of America,* 84(12): 4190-4194.
- Robertson, A. (1990) The politics of Alzheimer's disease: a case study in apocalyptic demography. *International Journal of Health Services,* 20(3):429-442.
- Roth, M., Tomlinson, B.E. and Blessed, G. (1966) Correlation between scores for dementia and counts of "senile plaques" in cerebral gey matter of elderly subjects. *Nature,* 209: 109-110.
- Rothschild, D. and Sharp, M.L. (1941) The origin of senile psychoses: neuropathologic factors and factors of a more personal nature. *Diseases of the Nervous System,* 2: 49-54.
- Sampson, E.L. (2010) Palliative care for people with dementia. British Medical Bulletin, 96(1):159-174.
- Satz, P. (1993) Brain reserve capacity on symptom onset after brain injury: a formulation and review of evidence for threshold theory. *Neuropsychology,* 7: 273-295.

- Saunders, A.M., *et al.,* (1993) Association of apolioprotein E allele epsilon 4 with late-onset familial and sporadic Alzheimer's disease. *Neurology,* 43(8): 1467-1472.

- Schenk, D. (2002) Amyloid-ß immunotherapy for Alzheimer's disease: the end of the beginning. *Nature Reviews: Neuroscience,* 3: 824-828.

- Shuster, J.L. (2000) Palliative care for advanced dementia. Clinics in Geriatric Medicine, 16(2):373-386.

- Small, N., Froggatt, K. and Downs, M. (2007) Living and dying with dementia: dialogues about palliative care. Oxford: Oxfoird University Press.

- Stamps, J.J., Bartoshuk, L.M. and Heilman, K.M. (2013) A brief olfactory test for Alzheimer's disease. *Journal of the Neurological Sciences,* 333(1-1): 19-24.

- Stettinius, M. (2012) Inside the dementia epidemic: a daughters memoir. Dundee: Lakemont Press.

- Stokes, G. (2008) And Still the Music Plays: Stories of People with Dementia. London: Hawker Publications.

- Strittmatter, W.J., *et al.,* (1993) Apolipoprotein E: high-avidity binding to ß-amyloid and increased frequency of type 4 allele in late-onset familial Alzheimer disease. *Proceedings of the National Academy of Sciences of the United States of America*, 90(5): 1977-1981.

- Summers, W.K., *et al.,* (1981) Use of THA in treatment of Alzheimer's-like dementia: pilot study in twelve patients. *Biological Psychiatry,* 16(2): 145-153.

- Summers, W.K., *et al.,* (1986) Oral tetrahydroaminoacridine in long-term treatment of senile dementia, Alzheimer's type. *New England Journal of Medicine,* 315(20): 1241-1251.

- Tanzi, R.E., *et al.,* (1987) Amyloid beta protein gene: cDNA, mRNA distribution, and genetic limkage near the Alzheimer locus. *Science,* 235(4791): 880-884.
- Tell, R. (2006) Dementia Diary: A Caregivers Journal. Michigan: RTP Press.
- Thomson, J.A., *et al.,* (1998) Embryonic stem cell lines derived from human blastocytes. *Science,* 282(5391): 1145-1147.
- Thuné-Boyle, I.C.V., *et al.,* (2010) Challenges to improving end of life care of people with advanced dementia in the UK. *Dementia,* 9:285-298.
- Tuke, W. (1857) *Laws of health*. Boston: John P. Jewett.
- Villeda, S.A., *et al.,* (2011) The ageing systemic mileu negatively regulates neurogenesis and cognitive function. *Nature*, 477(7362): 90-94.
- Villeda, S.A., *et al.,* (2014) Young blood reverses age-related impairments in cognitive functioning and synaptic plasticity in mice. *Nature Medicine*, 20(6): 659-663.
- Watkins, C.C. and Treisman, G.J. (2015) Cognitive impairment in patients with AIDS – prevalkence and severity. *HIV AIDS,* 7: 35-47.
- Weingarten, M.D., *et al.,* (1975) A protein factor essential for microtubule assembly. Proceedings of the Natural Academy of Science, 72: 1858-1862.
- Welton, J. (2013) Can I tell you about dementia? A guide for family, friends and carers. London: Jessica Kingsley.
- Whitman, L. (2010) Telling Tales about Dementia: Experiences of caring. London: Jessica Kingsley.
- Wilson, R.S., *et al.,* (2005) Proneness to psychological distress and risk of Alzheimer disease in a biracial community. *Neurology,* 64(2): 380-382.

- Wilson, R.S., *et al.,* (2006) Chronic psychological distress and risk of Alzheimer's disease in old age. *Neuroepidemiology,* 27(3): 143-153.
- Yaffe, K.D., *et al.,* (2010) Post-traumatic stress disorder and risk of dementia among U.S. veterans. *Archives of General Psychiatry,* 67(6): 608-613.